Witness Name: Lesley Jenkins
Statement No: WITN2662001
Exhibits: WITN2662002-
WITN2662006
Dated: 20 February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MS LESLEY JENKINS

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

I, Lesley Jenkins, will say as follows:-

1. Introduction

1. My name is Lesley Jenkins. My name and address are known to the Inquiry. I have recently retired from my permanent position as a senior lecturer at a University and I now work in private practice as a sessional therapist. I live on my own now as my children are both grown up although they remain close by and we are a close family because of our shared traumatic experience.

2. As a result of contaminated blood, my husband Paul Henry Jenkins was infected with HIV and hepatitis C and he died on 9 January 1997.

3. I met Paul when he was working for a community voluntary organisation in Cardiff around 1984 to 1985. I recall that I was on an interview panel for a job that Paul had applied for.

4. I went for a drink socially with Paul and we started a relationship. I believe this was around October 1985. We started dating at the time when Paul's first wife had recently left him. I understood that they had a difficult relationship.

2. **How Infected**

1. Paul had severe haemophilia A, also called factor VIII (FVIII) deficiency or classic haemophilia.

2. I can't remember Paul telling me explicitly that he was infected with HIV or hepatitis C when we started dating. In fact, I don't know if he knew for certain at the time.

3. Paul's condition meant that he has frequent bleeds and emergencies. His joints were sore and swollen. Paul would calculate his activities carefully around his treatment.

4. Paul was treated at the haemophilia centre in Cardiff. Initially he was under the care of Professor Arthur Bloom. After Prof. Bloom retired, Paul was treated by Doctor Dasani.

5. Exhibited before me at Exhibit WITN2662002 is a Consent Form that Paul has apparently signed in respect of home treatments for his haemophilia on 2 February 1984 which states that, "*I understand that such materials may carry the virus of hepatitis and may constitute a risk to myself and to others*". The form doesn't mention the HIV virus.

6. Exhibited before me at Exhibit WITN2662003 is an HIV working party form completed by Dr Dasani which indicates the date of Paul's first positive HIV test as July 1984. There are no blood test results in Paul's notes to confirm this. I am not certain of the date when Paul was informed that he had tested positive for HIV.

7. However, exhibited before me at Exhibit WITN2662004 is a letter from Dr Dasani dated 1 March 1996 in which he describes Paul as '*Blood Product recipient – HIV and Hepatitis C antibody positive for about 15 years*'. This indicates that Dr Dasani may have been aware of Paul's infection as early as 1981. Paul certainly wasn't aware until late 1984/early 1985.

8. Between 1977 and 1988 Paul was treated with a number of different types of Factor VIII including Profilate, Koate, Kryobulin, Haemofil, Armour, Factorate and Hyate.

9. Factor VIII was great because Paul could treat himself at home and anticipate bleeds. Having spent at least 10 days per month in hospital as a child, the home treatments gave Paul a lot more freedom.

10. Paul had told me about his childhood as a haemophiliac. He had been put into splints as a little boy which made his condition worse. He was educated initially at home and couldn't join in normal school activities. Paul also told me that he had a younger brother called William who had sadly died at age four when he had suffered a bleed to the throat. The hospital in GRO-D who were not experts in haemophilia, gave William a tracheotomy which killed him.

11. Paul was one of four brothers. Two of them had haemophilia and two of them did not. Paul explained to me that his childhood had been dominated with his health problems. His mum used to drive him into

Oxford to the hospital as she could not risk taking him to the hospital in GRO-D where William had died.

12. Then Prof. Bloom set up a Haemophilia Centre in Wales so he was able to be treated in Cardiff.

13. Paul grew up in Prof. Bloom's care and he was a family friend. He tended to treat the haemophiliac boys in his care like his family. I think it would be hard for Paul and his parents to conceive that Prof. Bloom knew that he was treating his patients with contaminated blood but this is what the evidence seems to suggest and I think it is part of the culture for people to cover their backs in the NHS. I can't say for sure what Prof. Bloom's involvement was with contaminated blood.

14. Paul was sent to Monmouth School for boys as a boarder because the school was able to accommodate his health needs and accessibility requirements. I am not aware of what, if any, blood products Paul would have received whilst at the school.

15. After Monmouth School for Boys, Paul began a degree at Cardiff University doing graphics and art. He had to take so much sick leave that by the time he reached the third year he was told by his tutor that it was not worth him carrying on as he probably would not achieve a qualification.

16. Around this time, Paul's family built their family business which was a pub in Sully, Penarth, called the Captain's Wife. Paul designed the logos, menus and promotional material. When he was around 23 years old Paul decided to do an English and media degree and moved to GRO-C to attend the University of Bournemouth where he lived for three years. Paul met his first wife there.

17. I never met Paul's first wife but I know that Paul had a stepson from her previous relationship. When Paul first finished his degree and moved

back to Cardiff both he and his first wife worked in Paul's family business. The family business was better able to accommodate his needs than a private employer.

18. I understand that Paul's first marriage ended in 1984 GRO-D GRO-D I don't know much about that relationship GRO-A GRO-A GRO-A I don't know what date this would have been.

19. We were starting to become aware of the link between blood products and HIV and hepatitis C infections and we were very careful to use contraception when we started our relationship. Things were very difficult at the start of the relationship but in hindsight I realise that Paul was under a lot of stress and pressure related to both his health and the end of his previous marriage.

20. I can't really say the precise time that Paul knew that he was infected with hepatitis C or HIV. This was a very painful topic for him, which he did not particularly want to talk about.

21. Our son GRO-B came along very quickly. I believe that we were using protection but there was an accident and I became pregnant.

22. I remember going to the Haemophilia Centre with Paul because becoming pregnant was potentially a huge problem and a crisis for us.

23. When I became pregnant I was strongly advised by Prof. Bloom to terminate the pregnancy. Paul wanted a termination as well but I did not want to do this as I felt distressed by the idea and I wondered if this might be my only chance to have a child. I had a monthly blood test to monitor the pregnancy and test me for HIV.

24. I was really frightened. I loved Paul but I didn't know if I or the baby would get HIV. Even though it was unbearable to keep it a secret, I felt

that I could not tell people. I had a couple of close friends for support but I felt unable to turn to my parents for support as my father took the news of my unplanned pregnancy very badly, and neither of my parents knew of Paul's HIV status.

25. Not many of the women affected by the contaminated blood infections where having babies at the time. There was not much research on HIV negative women having babies with HIV positive men. Fortunately, I never tested positive.

26. GRO-B was born in GRO-C 1986. I didn't meet Paul's parents until after GRO-B had been born in the hospital. They were supportive at that point. This was a very stressful time. Paul moved in with me when GRO-B was around 10 months old.

27. Looking back, I am glad that I went against the advice to terminate my pregnancy. I have never regretted having GRO- for a moment.

3. Other Infections

1. Paul was scrupulous in the way that he managed his treatment, looked after himself and disposed of sharps and swabs.

2. Paul was diagnosed with non-Hodgkin's lymphoma in April 1996.

3. Paul was admitted to hospital in November 1996 with a chest infection.

4. In January 1997 Paul had Pneumocystis pneumonia (PCP).

4. Consent

1. I don't think that Paul was aware of the risk of infection when he was using the blood products, at least until 1984. It was devastating to him

to discover that the products that had saved his life and given him his independence back were killing him at the same time.

2. I don't know whether or not Paul was experimented on or tested behind his back as this would have happened before we were together. I understand that Paul's mother, Pat Jenkins, was told in 1982 or 1983 that Paul had HIV by the dentist, Chris Lewis. She believes this to be before Paul had been told. Pat will provide more information about this incident in her witness statement to the Inquiry. Paul certainly wasn't aware until 1984/1985 so he must have been tested without his knowledge and the results concealed from him and removed from his records.

5. Impact

1. I don't know the precise point in time that Paul became aware that he had been infected. I believe that he had recently found out when our relationship started and I think he probably tried to tell me but I didn't really understand what he meant and how serious it was. I felt completely in a bubble at the time and something really changed in me when that information started to sink in. I was really frightened but I loved Paul. If I hadn't felt so strongly for him I might have left.

2. When my children were little, I agonised about talking to them about what was wrong with their Dad. I was determined to keep the matter private within our home. I remember Paul being absolutely terrified about catching something from the blood he was using. At one point I remember him being frightened that he had VCJD. People that he knew from the haemophilia centre were dying all the time. We went to endless funerals of fellow haemophiliacs who had died from AIDs related illnesses.

3. My relationship with Paul lasted for 11 years before he died which was nine years longer than we anticipated. We had to be vigilant all the time

and had a constant underlying neurosis about infections. It would have been easy to become miserable about it but Paul tried to just get on with it and not give up.

4. We got married five years into the relationship and I got pregnant again with my daughter GRO-B. I was tested twice for HIV during my second pregnancy which was a radical difference from the first time. I was still anxious this time but it was not as traumatic as it had been before.

5. I was lucky to have the support of my GP because when I went into labour with GRO-B it did not progress as expected and I had to have an emergency Caesarean section. Despite having tested negative constantly for HIV, I was made to feel that I would have been quarantined by the hospital had it not been for my GP's intervention.

6. I had been lecturing at a University until around 1996 but Paul started to become more and more unwell. I remember one time when I was on the phone at home to an examiner and Paul was ill in bed, he started to throw up blood into the bath. I realised then that Paul was getting sicker and I felt that I had not been paying enough attention.

7. In April 1996 Paul was diagnosed with non-Hodgkin's lymphoma and he had a cancerous growth in his sinuses. He had radiotherapy and chemo therapy and I had to take leave from work to look after him. These were the first occurrences of AIDS related illnesses.

8. Paul was 39 at this point and he suspected he wouldn't make it to 40. He had a 'Made it to 39' party instead which was a lovely occasion and all his friends and family attended.

9. Paul had been extremely ill over the Christmas period but he really made an effort for the family. After Christmas, he went into hospital for the weekend and had PCP and a serious chest infection. The consultant

x-rayed his lungs and Paul asked for help but the only relief that they could offer him was to increase his morphine dose.

10. Paul went on to suffer a series of other illnesses and infections until he died on 9 January 1997 aged 39. At this point GRO-B was 10 years old and GRO-B was only four.

11. I want to say that whilst I had a very happy 11 years with Paul and two beautiful children, Paul's infection with HIV was a huge burden on our family as it forced us to live a secretive life.

12. There was a lot of prejudice about AIDS and the way that it was transmitted and this was exacerbated by adverts on the television at the time pleading with people not to 'die of ignorance'. I felt that we were constantly living in a culture of prejudice and fear.

13. I fiercely protected my children and tried to give them as normal a life as possible in the circumstances. I think that since Paul died I have spent those years trying to compensate for the damage that's been done to my children having to go through such a tragedy so young.

14. If Paul had died so young from cancer you would expect sympathy and compassion but not with HIV and AIDS. In fact, we were strongly advised against talking to people about Paul's condition by hospital staff and social workers.

6. <u>Treatment/Care Support</u>

1. Paul was never treated for hepatitis C or HIV at all. I know that HIV medication was discussed in November 1996 but I think that Paul was already too unwell to undergo treatment. I will always feel that Paul was taken away from us too soon.

2. I don't know if Paul was ever offered psychological support. I know that he did used to talk to the social worker called Mary Dyke. I don't think Paul even spoke to his friends about his condition. He would not talk to his family about it either. I think this was because he knew that his Mum and Dad had already lost a son and he didn't want them to go through that again.

3. I don't think Paul encountered much stigma personally but he was extremely secretive about his condition and he was aware of others with the same condition having a hard time. He was strongly advised against talking about his condition by the social workers.

4. I have seen three or four different therapists over the years and I have benefited from it but this has been privately arranged and paid for by me.

5. I do not feel that I had adequate support when Paul died. The hardest thing was not knowing how to help my two kids. It was impossible to explain to a 10-year-old and especially a four year old what was going on.

6. I remember it was helpful that a character called Mark Fowler on Eastenders was HIV-positive and going through what Paul had gone through. This helped me to explain to GRO-B what had happened to his Dad.

7. It was arranged that GRO-B would attend a child bereavement group at a local hospice. In retrospect this probably did more harm than good because the other children were able to speak about how their parents died and GRO-B was prevented from doing so due to the stigma surrounding HIV. I remember that Children in Need were filming at the hospice whilst GRO-B was attending the bereavement group which really distressed and upset the children.

8. There was no support whatsoever for four-year-old GRO-B. She had a difficult time starting school and became selectively mute for a number of years.

9. I have really changed as a person as a consequence of becoming a widow so young and having to become independent and pay for everything. There were times when I had four different jobs in order to be able to support my family. My children and my career have been my priority as I have needed to make sure I could support us all financially, practically and emotionally.

7. Financial Assistance

1. I received a payment from the McFarlane Trust of £250 per month after Paul died which was almost insulting but at the time I really needed it in order to get by.

2. Paul was part of the initial group that tried to litigate against the Department of Health in 1989. Exhibited before me at Exhibit WITN2662005 is a Statement read at the Summons for Directions in that case by Mr Justice Ognall.

3. We were in a desperate financial state at the time and the Department of Health offered Paul £60,000 to sign away any further rights to legal action. We felt we had no choice other than to accept as we thought he might only have a year or two to live.

4. Very recently (around eight years ago) I received a payout of £80,000 from the Skipton Fund. I gave £35,000 to each of my children and then put away £10,000 to be able to contribute to my children's weddings

5. I have recently received a further payment of £66,000 from the Skipton Fund which is apparently a back payment to cover what they should have paid me over the years. It makes me furious to think I have

struggled for all these years and had to watch my home fall into disrepair unable to afford to fix it when the Skipton Fund should have supported me.

6. The support that has been offered is grossly inadequate in that it does not take into account the fact that I would have had on-going financial support if Paul had lived. No amount of money will enable me to come to terms with that.

7. I never got turned down for any payments or had difficulty with the applications but as I was working there seemed to be limited funds I could apply for. I have not wanted to be a charity case, but I just think more help could have been forthcoming.

8. Other Issues

1. When Paul was first diagnosed with HIV he felt very socially isolated. He was connected with some other young men in the same boat by a lady called Mary Dykes who was attached to the Cardiff Haemophilia Centre. Mary was instrumental in connecting Paul with other infected haemophiliacs and his social group went on to meet frequently in the Birchgrove pub.

2. Later on, together with another haemophiliac called GRO-A Paul set up the Birchgrove Group which was a support and self help group for haemophiliacs infected with HIV and hepatitis C through contaminated blood products in the United Kingdom. Birchgrove started in 1986, taking its name from the pub in Cardiff where the group first met. It then became a national organisation.

3. The aim of the Birchgrove Group was to actively support and inform those with haemophilia, HIV and Hepatitis C by organising meetings events and producing a magazine.

4. In 2003, 1,200 trees and a memorial stone were planted at Stratton Wood near Swindon as a living memorial to the 1200 Haemophiliacs infected with HIV.

5. Exhibited before me at Exhibit WITN2662006 is the Birchgrove Magazine from August 2004. The Inquiry will note the contents of this magazine includes a letter from Melanie Johnson MP and a number of articles and excerpts relating to the Skipton Fund and the calls for a public inquiry.

6. Paul was a major campaigner for justice for those infected with HIV through NHS contaminated blood. He always tried to obtain support for individuals and families going through the same stress and isolation that he had been through. Paul worked very hard for the Birchgrove Group although he did not like to be put out in front as a figurehead.

7. I remember that Paul's Mum was heavily involved with the Haemophilia Society and was an active fundraiser.

8. At the time many of us took the view that the Haemophilia Society didn't support families where someone had been infected with hepatitis C or HIV. They preferred to take a neutral role when they should've been campaigning on behalf of their members.

9. Paul was a lovely warm guy. You wouldn't notice his disability when you met him and he always persevered, choosing to work because it was important to him. Paul had a wicked and devilish sense of humour. He was passionate about the plight of the underdog. Paul was a kind and loving husband. He was a great father and did not want his disability to define him. He was devastated to not be able to be there to support his children growing up. I know he would be very proud of them.

Statement of Truth

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

Signed....... GRO-C ....

Dated........ 20. Feb 2019 ....