Witness Name: Steven Lewis
Statement No:WITN2435001
Dated: 5th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEVEN 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, Steven Lewis, will say as follows:-

1.Introduction

1. My name is Steven Lewis. My date of birth is GRO-C 1976 and my address is known to the Inquiry.

2. I am married with 3 children and working full-time as a Graphic Designer.

3. In this statement I will discuss how my Father Haydn Lewis and Uncle Gareth Lewis were infected with HIV, hepatitis B (HBV) and hepatitis C (HCV)

through receiving contaminated blood products. I will also discuss how my Mother Gaynor Lewis was infected with HIV by transmission.

2.How Infected

1. My Father, Haydn William Lewis, was infected with HIV and hepatitis C (HCV) through contaminated blood products that he was required to take due to haemophilia. He died on May 21st, 2010 following a battle with liver cancer (brought on by the hepatitis C) and after having had a liver transplant. He was 53.

2. My Mother, Gaynor Lewis, was unknowingly/inadvertently infected with HIV by my Father. GRO-C. She is 62.

3. My Uncle, Gareth Lewis, also suffered from haemophilia. He was also infected with HIV and hepatitis C (HCV). Gareth died on 13th December 2010 - just 6 months after my father passed away. Gareth had a stroke whilst on holiday visiting family in Spain.

4. My Father and Uncle were diagnosed as having haemophilia in the late 1950's. Their condition was considered mild. Their conditions were treated in the normal way for the time. In the 1960's they started to receive Cryoprecipitate. This continued until around 1978. Factor VIII was used after this.

5. As a child, my Father attended hospitals in Cardiff which at that time, were the Cardiff Royal Infirmary (CRI) and Llandough Hospital. In the mid 1970's he started attending University Hospital of Wales (UHW). His Consultant was Professor Bloom. Other doctors involved were Rd. Pete Collins, Dr. Dasani.

6. Dad believed that he could trace back the chain of infected Factor VIII treatment as beginning around the time my brother Paul was born, which was in late 1978. In 1978 my Dad had a bleed in the leg. He did not respond to Cryoprecipitate so Factor VIII concentrate was required. In 1980 Dad had an

injury to his wrist. He again did not respond to Cryoprecipitate so Factor VIII concentrate was required.

7. Dad developed an inhibitor to Factor VIII and received high doses treatment including **imported** concentrates. I understand from medical records he seroconverted sometime in 1979-82.

8. Dad and Uncle Gareth were told in 1985 by Professor Bloom that they were infected with HIV. They were told at the Haemophilia Unit at UHW. My parents assumed it was a death sentence. Back then you regularly heard of people dying from HIV/AIDS. In later years, I recall speaking to my Dad about how this must have felt, he said that his thoughts were my Mum and us boys. He wanted to watch us play and grow up happy. He was told he had maybe 3 to 5 years to live, so he knew his time was limited.

9. I recall during the 1980's my Father infusing at home. One shelf of the fridge was always full of meds. It all seemed strange to me, but seeing my Dad laid back with a needle in his arm, paying visits to the hospital, me helping out, became the norm during my childhood.

10. In the early 1990's dad had been suffering from a pain in his side. My father asked Dr Dasani whether he had hepatitis C (HCV). Dr Dasani confirmed this. My parents both recalled being told in a 'matter of fact' way. When Dad was told by Professor Bloom that he was HIV positive, he was offered *some* counselling but nothing substantial. There were no real support networks in the 1980's for victims like my Dad. No written materials were given.

11. My Dad and Uncle, along with fellow haemophiliacs from the Heath hospital (IHW) 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. Dad relied a lot on the social workers for support. Mary Dykes and Linda Ford were extremely helpful. They were more like counsellors but we were never given any formal counselling.

12. My Mum was infected with HIV in the mid 1980's, it was sexually transmitted. My parents weren't aware of the risks back then. My Mum was told she was HIV positive in 1988. I believe Mum had a HIV test after my Dad was diagnosed with it, but it came back negative. They both believed this was a false negative and she was infected prior to my Dad finding out he was.

13. I don't think adequate information was given to my parents and Uncle in order to understand and manage the infection, especially in the early days. But I also think the whole health sector was in the dark with regards to a lot of things. They were under pressure, politically and socially. Decisions were made by Politicians which were financially, not morally, motivated. I'm sure many of the high-ups knew of the risks they were taking, importing unclean blood products, but I do believe the vast majority of regular doctors and nurses did the best that they could with what they had at the time.

14. Doctors, Nurses, Social Workers and Counsellors should have been better educated, and earlier. "Marketing" should've been a lot more sensitive to people actually living with the disease. Regularly updated news on treatments should have been available. Specialist advice, for the infected and affected should have been offered. My parents should've been advised how and when is best to speak to their two children about their condition.

15. I definitely think information could've been provided earlier. The Government were slow to react to the crisis and were complacent, ignorant and happy with the narrative that it was a "gay-only" disease. They should've realised the extent of the problem and funded research into it a lot earlier.

16. If more adequate research was made earlier, my Dad might have known earlier. And if adequate information was given, my Mum might not have been infected. To take it back even further, if my Dad and Uncle had known earlier that the blood products they were being treated with were from unclean sources and the risks therein, then they could've made a decision to not accept this treatment.

17. I feel the manner in which the results of tests were given to my Father and Uncle were pertinent to the time. In 1985, on average people with the disease were living for 3-5 years, so doctors told them what they believed. I think it should've been handled with more empathy and support available. I do think the manner in which my Father learned he had hepatitis C (HCV) was disturbingly cold and unprofessional.

18. I do think information about how HIV can be spread through heterosexual intercourse should have been given to my parents earlier. They never had unprotected sex after my Dad was diagnosed in 1985, so either my Mum was infected prior to this, or the subsequent test she had wasn't reliable.

19. I don't know if my parents were given information with regards to the risk of infection to me, or my brother. We weren't given any information pertaining to the risk of infection, as we didn't know we were in any danger of it.

20. Later on, after my parents had spoken with me about their condition, I did learn more about the risks of infection. Talking with them helped, as did talking to family and friends who knew. I read books and other materials. I met with a social worker regularly. We played snooker and talked about life, my parents, how to cope with things – however they turned out. It helped a bit.

3.Other infections

1. Dad had hepatitis B (HBV) which I believe he contracted in the 1960's from blood products. He was led to believe that it was a harmless virus and would just give him a bit of jaundice.

2. In 2000 my Dad was told he had received blood from someone who had died from vCJD. This greatly upset him. It upset me too. He 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. Nice. .

4.Consent

1. I'm not sure on this but my Mum will have discussed this in her statement. Bloods were taken, lots of vials taken. They must have been doing tests behind the scenes as they used those to diagnose his HIV in 1985.

5.Impact

1. It affected my Dad's mental and physical wellbeing tremendously. Mentally, there was the uncertainty of it all, the worry of not being alive for long, the worry of not hugging and kissing me and my brother, the guilt he had to live with after my Mum was infected, seeing his younger brother go through the same illness he was, the fear of what others were thinking about him and his family, the affect it would have on his wife and kids.

2. I always thought of my Dad as a big, strong, man. Even though he was only 5' 10" tall and I outgrew him in my teenage years (I settled at 6' 2"), he was still like Superman to me. I think it was partly because he was a naturally handsome guy. Also, I think he retained that powerful stature from years of physical labour, sawing, hammering, lifting, etc. But I also felt that way, subconsciously, because of years of seeing him go through the things he did. Regular physical hurdles were cleared with grit and stubbornness. He was always back on his feet earlier than expected, after bleeds in his knee, knee replacement and later ankle fusion surgeries. He even recovered from his liver transplant much earlier than experts said he would. He never complained about coughs or colds.

3. He did become tired though. I could see that in him. I recall how frustrated he would become not being able to finish a job to completion. He didn't like to let people down, so he eventually made the decision to give up work. I know this saddened him greatly. I used to work with him a lot in my teenage years, I know how much pride he took in his job and the satisfaction he got from a good day at it.

4. It also affected his mood. He didn't have much patience for nonsense and bad behaviour, so we'd get shouted at sometimes. But at other times he was extremely loving and generous, spoiling us with random gifts, not just on special occasions. I'm not saying it was a difficult childhood, far from it, but I clearly remember some crazy arguments and incidents happening. Not just between my parents, but the whole family at times. All the things I've described affected my mum too and we weren't best kids in the world, so I imagine it was doubly difficult for them.

5. Thinking back, aside from all the physical and psychological things I've stated, I'm also convinced both my Mum and Dad have suffered from/are suffering from mental health issues and/or depression. I know my Mum and Dad sought help for social anxiety and anger management respectively.

6. Dad began receiving AZT treatment for HIV in 1992. I was 16 at the time, I recall it was not pleasant. It made him quite ill, like having anaemia.

7. Dad and Mum were physically attacked in around 1995, by a group of drunken idiots. Dad had a broken nose which he had to have operated on and various other injuries and bleeds. My Auntie spoke to the Police and had a statement taken as she was with them when it happened. She told the Police about my Dad's condition. A few days later, the Police contacted Mum and Dad to say it was best not to prosecute, due to the public stigma and the fact it might get turned back on them because they didn't make it clear about the haemophilia and HIV when the altercation began. Ridiculous! At 19 years old, I remember being absolutely furious about this.

8. Dad had hepatitis C (HCV) treatment in early 2000, I think with the hope of curing him of it. He was treated with Interferon and Ribavirin and Amantadine. The treatment lasted for about 6 months. It was horrible for him and a difficult time for all of us. The Interferon treatment caused extreme fatigue, confusion, cramps, headaches, bad moods – among other things. My Dad was in bed most days, he was always shivering, feeling cold.

9. He was only on interferon for around 6 months when it should have been longer. Unfortunately, 3 months after treatment the hepatitis C (HCV) virus was back. It was like watching someone having a terrible dose of flu all the time. It was difficult for me as it also made him very angry and temperamental. He was difficult to live with. He was having lots of rows with my brother and I. It was a really stressful time for everyone.

10. As well as these things, he also had bouts of jaundice and periods where he would suffer from severe migraines. I don't know if this was from stress, the medication he was on, or a combination of things. Seeing my Dad suffer was incredibly worrying, frustrating and challenging for me. As was dealing with all the arguments.

11. Throughout the time after my Dad's diagnosis, 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 us. It had a great effect on his overall mood and the anger and frustrations he felt seeped into his family life. Which in turn, affected my Mum, me and my brother.

12. Before my Father and Mother's illness we had been reasonably comfortable, financially. We were not well off but were quite stable. My Mum had worked in retail in the past and my Dad had his own business. My Mum ended up staying at home to raise us, while also looking after my Dad when he wasn't working. After my Dad retired from work, we lived on Welfare Benefits and hand-outs from the Macfarlane Trust. It greatly frustrated my Dad that he couldn't help me out more, financially. Especially when my partner and I were buying our first home and renovating it. He helped out more than enough, as far as we are concerned. We couldn't have done it without him.

13. All these things affected the social lives of my parents. Socialising was always difficult, not just for physical reasons. Mentally, we always worried about having to delve too deeply into talking about our family lives. We were scared of the reaction and the further questions, then the future. There were

meet ups with the Birchgrove Group and family trips with Haemophilia Wales. We went on family holidays. My mum and dad didn't go out much and preferred to stay in with close friends.

14. I suppose the impacts of it all for me began when I was around 8 or 9 years old, I didn't know about my Dad's condition, so I didn't know any different. Whatever happened was the 'norm' for me. But when I think back, I can appreciate this is when a lack of physical contact between my Dad and I began. I can't recall many kisses or cuddles. I remember being carried, holding his hand as we crossed a road, ruffles on my hair, things like that. There was a definite sadness and frustration there, even then.

15. Going into my teenage years I remember him being tired a lot and not being able to take part in things like sports and games with us as much. This was confusing and frustrating for my brother and I. He did his best when he could though, hopping along.

16. My teenage years was when I started to argue a lot more with my parents. I was a stubborn kid, but I'm sure I was just copying what I knew. Growing up, both parents going through what they were – being tired all the time, the side effects of treatments, the constant worry – many disagreements were settled impulsively and emotionally, with shouting and storming off! There were many occasions which should've been handled better.

17. I don't want to make out it was always like this, but I remember a number of times over those years, laying in bed at night and listening to shouting and arguing. I'm sure it was only ever if they'd had a few too many drinks and emotions were running high. I do remember thinking that my Dad was losing his mind at times! Regardless, things like this affected the way I thought and acted and, obviously, my education in school the next day.

18. As I got a bit older I started to suspect things weren't right. I questioned things in my mind, as stated previously – the hushed conversations, the looks from people, the reaction to news on TV, Mum's increased hospital visits and

letters to her from the hospital. I wasn't stupid, neither was my brother. I think we knew, but personally think I stored it away somewhere in the back of my mind.

19. I remember speaking to a close friend of mine when I was probably around 15 and telling him that I thought my Dad, perhaps my Mum too, were ill. I told him it might have to do with HIV or something. He was a great friend to me then and he still is now. Thinking back, this is something I struggled with for years. Hearing quips and jokes about AIDS in school and hanging around with mates... even before I knew about my parents and Uncle, I knew it wasn't the kind of thing you should be joking about. This affected my personal relationships later on, after my parents had a proper chat with me.

20. I recall that day vividly. I was in my friend's garden, who lived opposite us. My Mum called me in and said they wanted to have a chat. I think I knew then, I could see it was serious. They both took it in turns to explain to me what happened, how it happened, that my Mum and Uncle were also infected. We were all very close, it was a heart-breaking, surreal 20 minutes or so. They stressed to me that treatments were improving and people were living longer, but it was still hard to take and difficult to come to terms with. However much I learned about it, how I shouldn't be pessimistic, I still feared the worse. As any, regular, moody teenager would I suppose. I don't recall what happened directly after this, but I do remember my parents speaking to my younger brother. I guess they figured they had told me so it was unfair not tell him. He didn't take it well and disappeared to his friends for a few days. I remember my brother actually being angry at them for not telling him earlier, that he wasn't stupid. I felt for everyone in this situation at the time.

21. I agree with their decision to wait until my brother and I had grown up (i.e. left school) to tell us. The stigma of HIV/AIDS back then was terrible. I recall being scared of the adverts the Government released in the 1980's. I remember the jokes and horrible comments in school. There was never an easy time, something important was always happening in our lives. But I also feel if we were told earlier, maybe we could have handled it and our parents

wouldn't have had the struggle of hiding it from us. We could have had counselling, which may have helped us cope with it emotionally throughout our adolescence instead of it being this unknown presence in the background the whole time.

22. In the early 1990's my Uncle Gareth began taking us to Cardiff City FC matches. It became a regular thing. It was great to bond with my Uncle in this way. We even used to travel to away games all over the country, with my brother and cousins. We carried on this tradition over the years and still did after he died in 2010. I now take my son to watch them, I still feel like my Uncle is there with us. It seems silly but I feel like I see ghosts down there sometimes, out of the corner of my eye.

23. He was known as "uncle Gary" down the City even by friends of ours who weren't related to him! He was just one of the lads and the hole he left was impossible to fill.

24. Gareth didn't hide his condition from anyone. He didn't give a shit what anyone thought. He was a proud man and walked with his head high. I was proud to have him as my Uncle. When my parents needed a break, he was there to look after us. When my Dad had one of his many hospital visits, he was there for us. As I said above, he took my brother and I under his wing and treated us not so much as "nephews" but equals. He was an older, inspirational, figure to us. We respected him, but we could get away with stuff around Gary that we wouldn't dream of saying or doing around other family members! Basically, the coolest Uncle two teenagers could hope to have.

25. After I was around 16, forming close bonds with people became really difficult for me and I began to develop some social anxieties. I would get close to someone I really liked (especially a girl), then back off inexplicably. I don't know if it was *"don't get close to this person, you might lose them like you might lose your parents"* or more *"don't get too close or you'll have to talk about your feelings and your fear of Mum and Dad dying"*. It was another source of frustration for me, I didn't like it, I hated myself for it.

26. I really didn't know how people would take it. Like, would they consider ME a risk to them, because I was the son of a couple of AIDS victims? It sounds ridiculous now, but that's what I thought. I knew that's what some people were like, I actually had friends who were ignorant like that.

27. There was one time, a friend was over our house. Eastenders was on TV. Someone on the show shouted "AIDS SCUM" at another character. My "friend" laughed at this, it was an awkward uncomfortable moment. I told him I had to do something and he had to go. I never spoke to him about my parents after this. I presume he found out, as a lot of my old friends did, when they saw my dad and mum in the newspapers or on TV during the later campaigning years.

28. For this reason, I kept certain friends close and others as more social buddies and acquaintances. It was a defence thing, I feared the confrontation of it all so I avoided it in all but a few close friends going from my late teens into my twenties. I even avoided it with my own parents, the ones who were actually suffering. I didn't want to talk deep about stuff, it hurt too much. I do recall speaking on occasion with close friends of my parents and also my Mum's sister about things. They were a source of comfort for me, it helped me realise that even if I lose my parents, I still have people who care for me around.

29. Around this time (mid-late 90's), I started having kind of counselling sessions with a social worker my parents knew. His name was Tim Hunt, he was nice. We used to meet for a game of snooker and a chat once a week. It really helped.

30. It was still a stressful time though. Doing my GCSE's, then A-Levels, with everything else going on. I took time off education, I didn't feel I could handle it mentally. Things at home improved, there were less fights. My Mum helped out loads, getting me up for work and stuff. I went to college and later, University. The distance helped our relationships, I think. Going back home

was great. I wasn't so closed off with my parents. I made some good friends and formed some close relationships, but I still didn't open up to anyone during this period about how I was feeling, about my parents, etc.

31. There were times when I'd be out with mates, drinking and stuff. As the night went on, the more I drank, the more emotional I would get. Even if we were all having a great time, there would come a point where I would just have to go. Quite often, I didn't even explain, I just disappeared. Other times I just ran, not with any location in mind, just to get away. Shamefully, my best friend once found me sat in a phone box miles from where we were, just crying. I think I needed better coping mechanisms!

32. I think I coped better in University as I was with a whole new bunch of people. It was a kind of fresh start. I still had ups and downs. I struggled to concentrate for long periods. I would daydream a lot in lectures, thinking the worst as usual. It was tough being away from my family. I really had to knuckle down and work had to achieve what I did. My Dad came and visited me quite often when I lived away, he would bring me food my Mum had cooked. This was good, for both of us I think.

33. After graduating and moving back home, our relationships really improved. We still had the occasional row, but I felt like I could talk to my parents openly and truthfully about things. Around this time, my Dad and I would catch a pint at the pub more often. A pint or two, a good chat and maybe a game of pool. Good times. A lot of problems were worked out this way.

34. In the late 90's I felt a real focus on getting my life together and trying to make my parents proud. I got my first professional job after graduating. It was tough at first and I struggled a lot mentally and emotionally. My Dad and Mum helped a lot.

35. In the early 2000's my Dad spent a lot of time on his computer researching the infected blood scandal. Many a night I would wake up and he would still be up, on the computer. He channelled his frustrations into this research. It

gave him a focus and a purpose. We supported him 100%, even though it became a bit much at times (talking about it day and night was hard work, mentally).

36. I "met" my future wife, Rhian (We'd known each other for years, our parents were friends). We were already friends, so in this instance the trust was already there. She had recently lost her father (my Dad's best friend) so it was a very difficult time for everyone. We were there to support each other. I could be totally honest and open with this person. She knew my parents, knew about everything. It felt so natural and easy. This period may have been the happiest I'd ever felt. We bought a house. My Dad helped us out loads. It took us a year to fully renovate and he was there with us the whole time. It was very hard work, both mentally, physically and financially. Our son was born. Our parents were overjoyed, everyone was. My Dad was a grandfather, he was so proud and loved little GRO-C very much. It filled my heart with joy seeing him playing with my son.

37. It was during this period (2008ish) that my Dad was diagnosed with Liver Cancer. Everything was going good, it seemed so unfair. The impact of looking after a new baby, a new house, my job and this on top. I found it an extremely stressful and emotional time. My new fear, on top of the old ones, was that my son would grow up without a grandfather. I hated that thought and it still makes me angry and sad.

38. Dad had a liver transplant. We travelled a lot back and forth Birmingham during this time. Again, it was a difficult time, juggling all the different pressures life throws at you. We didn't deserve this. The transplant went well, he recovered and came back home. Not a year later, the cancer was present in the new liver. This was a tough pill to swallow. I remember feeling the hope dwindling, but I think I was in denial that he could die. He wasn't just my Dad, he was my friend and hero. He couldn't die, he was indestructible!

39. Tragically, in May 2010, he passed away. I thought I was prepared for it, but it broke me. I put on a brave face but I was crumbling inside. If my wife and son weren't there, I don't know what I would've done.

40. It's impossible to describe how influential he was to me. Everything that I am (good and bad!), I owe to him. Growing up, my brother and I never saw him cry. After every injury he sustained and every illness he struggled with, we never heard so much as a groan from him. This was incredibly inspirational to me. Hard working, doggedly determined for justice, but also philosophical about the most polarizing issues. Forthright, funny, clever, humble, forever truthful and always looking to protect those around him. He was gone, but those are the things that helped me through. If I've inherited even a fraction of his persona and values, then I know I'll be doing OK. And I know my children will be OK because of this. My Dad always stressed that no matter what you're going through, there's always someone worse-off. I always try to remember this.

41. The last conversation I had with my Dad was when we knew his time was almost up. It was 2 or 3 days before he died. My brother and I were in his room at the Hospice with him. He was lucid, but not the whole time, so it was a difficult chat. I couldn't think of what to say. I told him I loved him, I was proud to have him as my Father and that my brother and I would look after Mum. That last part is still a thorny subject, for me. Without going too deeply into it, I feel like I've failed in that regard and its not for lack of effort on my part. It's a constant struggle for me, every day.

42. Six months after my Dad died, my Uncle Gareth passed away. I've mentioned the circumstances previously, but I need to reiterate how much of a double blow this was. It really hit me hard and changed me in a number of ways. I had dark days where I wouldn't want to see or speak to anyone. I just wanted to be alone. I felt like life was pointless for a while. I'd be up and down most days.

43. The next few years were the same. I felt sad a lot but my family, my son, brought me up and gave me a focus to keep going. I got married and we had a second son (which I helped deliver in the bathroom, unexpectedly! I'm sure my Dad would've loved that). But everything felt like it was getting on top of me and I couldn't cope with it all, I felt like not only had my heart broken when my Dad died, but something in my brain did too. I also felt like my Mum had changed and, in a way, I'd lost the person she was prior to my Dad dying. This affected my social and work lives in different ways, it was really difficult to balance everything.

44. At the insistence of people close to me, especially my wife, I sought help. I spoke to my GP about it – he knew my family situation – and he diagnosed me with depression. He started me on medication. I began to see a counsellor once a week. Things improved slowly. I still have moments like I did 5-10 years ago, but not as often. It's something I work on and struggle with every day.

45. As previously stated, the effects of everything on my education and later working life were great. Not being able to concentrate, being down a lot and keeping an emotional distance from colleagues were the biggest factors.

46. The effects on my dad were even greater. I used to love working with him, but he had to close his business in the 90's and retire altogether in the 00's. This was a tremendous blow to him, to his confidence and self-worth as a husband and father. I know it really bothered him. It didn't bother us; we wanted him to take it easy. We were sad for him, obviously, but it was good to have him around more. It was great to have him help us with our new house when we bought it. His expertise was invaluable.

47. Over the years, I've tried to imagine the pain and guilt my Dad must have felt at the time and going forward. How to cope with the knowledge that they might not live to see their sons grow up and the thought of us growing up without parents. Having a wife and children has given me a deeper appreciation of this difficulty, it must have been a nightmare for them both. I

recall this being a very emotional, turbulent time for the family, but I didn't know why.

6.Treatment/Care Support

1. In 2008 he began to experience pains in his side. He put a brave face on it but I suspected something was wrong. A routine blood test showed one of the blood levels were raised and the hospital asked him to go back in to the repeat the test immediately as they needed to check 'something'. At the time, my Dad presumed they'd taken the test wrong, or something.

2. He had scans and tests at UHW. They revealed tumours in the liver. My parents informed me and my brother at the same time. I think we both reacted in the same way, with a kind of numbness and disbelief. But also, angry because it was obviously brought on by the hepatitis C (HCV).

3. Things got worse and in December 2008 he went to Queen Elizabeth hospital in Birmingham to be assessed for a liver transplant. Dad was later put on the transplant list. My parents (and me, just in case) had to be on standby for that phone call. Bags had to be packed and be ready to leave for the hospital right away. This was another very difficult time for me and the family. I now had a partner and a baby (born in GRO-C 2009). My Dad was a grandfather, which made him very proud and happy. He wanted to see his grandson and future grandchildren grow up, we wanted our kids to have a grandfather. The tumours were getting worse. He was in a lot of pain. His stomach was swelling up.

4. Eventually, in March 2009 the call came. I said goodbye to my Dad, but not in the usual "catch you later!" kind of way. I told him I loved him, we hugged and I went through moments of thinking I might not see him alive again. I didn't know if he was strong enough to get through it, or if anything would go wrong.

5. The operation in Birmingham was done GRO-C
GRO-C

GRO-C

GRO-C The operation went well. Dad 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 normally took 5 minutes. He got to see more of his grandson.

6. Unfortunately, the donor liver that Dad received was also hepatitis C (HCV) positive. We were told at the time, but it was a case of "beggars can't be choosers". So it was all kind of bittersweet. Having a new liver meant no more haemophilia, so this was new and strange for is, however short lived it was.

7. Initially we were told the cancer had cleared but that was short lived. By September 2009 it was back and was aggressive. Dad underwent a procedure called Chemo-embolization. It involves laser treatment to accurately target the tumours. They are then filled in with a substance to stop any growth. This is the only operation that I recall Dad regretting having. He regarded it as worse than the transplant. Again, this was a very stressful time for me and the rest of my family – and all within the first year of my son's life.

8. From the beginning of April 2010 dad was having palliative care at the Holme Towers Hospice in Penarth. Nurses would come to the house sometimes and he occasionally stayed at the hospice. Juggling a full time job and a new baby, on top of everything else was difficult. I visited and helped as often as I could. My Dad stressed that he didn't want it to affect my life at all, that I should concentrate on my family. I think I was in denial, but my Dad knew he was dying. He made video diaries and talked quite frankly about it.

9. Tragically, for me, my family and everyone who knew him, my Dad spent one final week at the hospice and passed away on 21 May 2010. His death was mentioned on the BBC programme 'Newsnight' as he had appeared on it on a number of occasions.

10. When Dad died Mum 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. Mum offered to dress him but was declined. This was very disappointing at the time and added unneeded stress. This whole process was unusually long. Dad's funeral was on 2 June 2010.

11. I would like to add that it was a source of frustration over the years hearing about advanced treatments for HIV, hepatitis C (HCV) and Liver Cancer around the world and my Dad not having access to it. Be it for financial reasons, or because we can't have every new thing available to us on the NHS in the UK. When I was younger I always thought it was strange that my dad had to go to the hospital to see the Dentist.

12. There was no real support networks in the 1980's for victims like my Dad. Along with fellow haemophiliacs from UHW 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.

13. It gradually became a more formal organisation. 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 GRO-A GRO-A. The group was a great mutual support but you also became aware that its members were dying. My family were always going to funerals. By the time I was an adult I remember talking to friends about the amount of funerals I'd been to. It was/is a ridiculously high number.

14. No advice or support was given to me as I wasn't aware of my parent's condition yet. I assumed anything related to Dad's health was due to the haemophilia. It was only later, when I was in my teenage years, that I began to question things in my mind. Things didn't feel right. Conversations were hushed when I entered a room, mum paid more visits to the hospital, reactions to things on TV and in the newspapers, overhearing parts of heated

discussions and occasional arguments. It was a weird time, I think I knew it but I put it to the back of my mind.

7.Financial Assistance

1. Dad became involved in litigation in the UK in around 1987. My Uncle apparently told him there was a lawyer who was taking on haemophilia cases. I believe they were 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. These payments were never regarded as compensation - they were 'ex gratia'. An apology for the tragedy was never given, neither has anyone taken responsibility for what happened.

3. Dad received a payment of £20,000 from the Skipton Fund and then later, a further payment of £25,000 from them because he met the criteria due to liver cancer.

4. I recall my parents exclaiming how difficult the Macfarlane Trust (MFT) were to deal with a number of times over the years. On one occasion, around 1988, my parents were doing work on the house with the view to making it suitable for Dad to live downstairs if (or when) he became too ill. We needed £5,000. The MFT denied them this. They regarded this as a luxury, not a necessity. It was only when my Mum got very upset while on the phone to them that they relented. It shouldn't have come to that. Financial decisions shouldn't have been made based on sympathy for something, the facts should've sufficed. All these things directly affected me and my brother. We didn't like to see our parents upset, sad or angry. We wanted help too.

5. My Dad found it impossible to get life insurance or any mortgage insurance. And very difficult to get travel insurance.

6. Although I was obviously helped financially by my parents throughout my life, I personally have never applied for, or received any financial aid. I didn't think I was eligible. I recall my Father thinking I should be though (Category 12?).

8.Other Issues

1. I know what spurred my Dad and Uncle on was the tragic death of Colin Smith. Colin Smith was born in 1982 with haemophilia. He died at home from AIDS at the age of 7 in 1990. I remember meeting him when I was also a kid. I was older than him, I felt sorry for him, he was a quiet kid but full of life and joy. The news of his death when I was 13 or 14 was really tough. I felt gutted for his parents. There should've been a proper inquest about this individual case. My Dad fought to try to find the truth about this tragedy to his dying day. He wanted openness, honesty and transparency from the Government. The opposite things to what previous Governments had been.

2. Dad became a member of Tainted Blood in around 2006 - this website was set up by GRO-A and my uncle Gareth Lewis as an online support network and for campaigning news. Dad helped out as secretary.

3. Dad and his friend, GRO-A worked together on compiling a Timeline of events to do with blood and blood products. They made sure everything was sourced that was uploaded. They spent a LONG time on this. It is still regarded as a definitive history of the scandal.

4. While I'm happy that the Infected Blood Inquiry is happening, it's all very bittersweet. We wanted this for years. I wanted my Dad and Uncle to be alive to witness it and be a part of it. I'm happy that my Dads work and his story are helping, but it doesn't make it easier for me.

5. This has brought it all up again, for me and the whole family. It like I'm reliving it, in a way. It is very hard and I can feel it affecting me, even now. My wish is that this will bring an end to a fight that my family has always fought for and we can move on, finally. We won't ever forget the people

we've lost, but to get a real sense of closure would be immensely satisfying and a great help going forward.

Statement of Truth

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

Signed... GRO-C

Dated........5/3/19..........