Witness Name: DEBRA THIANG SU TODD
Statement No: WITN1565001
Exhibits: WITN1565002 – WITN1565008
Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF DEBRA THIANG SU TODD

I, DEBRA THIANG SU TODD will say as follows:-

Section 1. Introduction

1. My name is Debra Thiang Su Todd (nee Birtwistle). I live at GRO-C GRO-C I was born on GRO-C 1971. I am a full-time mum and I live with my partner, Neil, and our three young boys.

2. I make this statement as an infected partner, as my ex partner, Stephen GRO-B was infected with HIV and Hepatitis C (HCV) as a result of receiving contaminated blood products. Steve died in 2016.

3. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are referred to in my statement or annexed as exhibits.

Section 2. How infected

4. I was in a relationship with Steve from April 1997 to March 2003. When we met in 1997 I was 25 and he was 26 years old. I met him in a nightclub while I was studying for my PGCE (Post Graduate Certificate in Education).

5. Steve had mild Haemophilia A. He was under the care of Dr Cheng Hock Toh at the Liverpool Royal Hospital. I believe Steve received Factor VIII (FVIII) as and when he had a bleed, but I cannot be certain that he did not receive any other blood products. I recall Steve and his family telling me that he should not have had treatment because he was only a mild Haemophiliac and didn't actually need it as often as he was given it.

6. I do not know when Steve was given infected blood products but I do know he was a child.

7. My understanding from what Steve and his family have told me was that none of them were given any information or advice about any risks of being exposed to infection from blood products.

8. Steve was infected with HIV and HCV, as a child, through FVIII. I was then infected with HIV through Steve.

9. Steve was told he had been infected with HIV and HCV when he was 14 years old. I believe his parents were told when he was 12 years old, via a letter.

10. I knew from the beginning of our relationship that Steve was a haemophiliac but it was never a big deal. I did not find out that he had HIV until 2002.

11. I had a sexual health screening around 1995, so when Steve and I got together I informed him that I knew I had no sexually transmitted diseases. I was part of a medical study in Manchester and having a sexual health screening was required before you could participate. I remember having a conversation with

Steve about the fact he would be checked for infections all the time due to his frequent blood tests. I remember saying to him 'so you are okay aren't you?' and his answer was 'yes'.

12. We used condoms for the first 18 months of the relationship as Steve insisted. I was on the pill as well so as our relationship progressed I did think it was strange. We moved in together around autumn 1998. I questioned why we were still using condoms as I believed he was checked in the hospital and I was checked during the medical study, and as we were being faithful to each other there was nothing to worry about. Steve said it was because he did not want me to get pregnant and it's better to be 'double sure'. Then one day, we both agreed to stop using condoms; this was sometime between autumn 1998 and autumn 1999.

13. I was ill for 2 weeks in October 1999. I now know that this was when I seroconverted and became HIV positive. Steve and I had only been in our new house a few weeks when I got a bad case of flu, soaring temperature, a rash all over my body, and severe vomiting. Steve took me to Chester Hospital A&E Department. Steve failed to mention at this point that he was infected with HIV and that I was at risk and this may be why I was ill. The hospital sent me away with a diagnosis of possible glandular fever.

14. For around 18 months after this illness, I frequently got ill, having ear infections, and chest infections, one after the other. I always had a cold and I could not shake it. I had gone from a clean bill of health to being perpetually ill. I visited doctor after doctor to try and find out what was wrong with me. But no-one could come up with an explanation. No-one even mentioned HIV. I went to an immunologist at Leighton Hospital to try and get a diagnosis. At Leighton Hospital they sent me for tests, but not a HIV test. As a heterosexual woman in a monogamous relationship, I believe I slipped through the net.

15. Steve had always been treated at Liverpool Hospital and he kept me away from his medical team. My GP had never met Steve's GP. My GP did not know

Steve had Haemophilia, if he did alarm bells might have gone off and I could have been tested for HIV.

16. Eventually I met a nutritionist who diagnosed candida overgrowth and after a radical change in my diet and lifestyle I started feeling better- except for the fatigue which I put down to working long hours as a primary school supply teacher. I soon put that period of chronic illness behind me and got on with my life without giving it a second thought. Throughout all this time HIV was never mentioned by Steve or his family.

17. In 2002 Steve got ill during the summer while we were away in Greece. He got shingles but he brushed/laughed it off. We came back from holiday and it was all forgotten. In November 2002 he suddenly got really ill again. He went into Liverpool Royal Hospital to get checked out and spent a week in hospital with encephalitis. This was the first time his medical team knew I existed because he had not told them about me.

18. They sent Steve home with medication but the day after Boxing Day, in the early evening, Steve started burning up and became ill. We thought it was the alcohol so he went to lie down. I kept checking on him but he was getting worse. He had a rash all over his body. We ended up getting an ambulance and he was blue lighted to Chester Hospital.

19. From Chester Hospital Steve was blue lighted to Liverpool Hospital at some point during the night. Steve's family and I were there at Liverpool Hospital and it all just became crazy. Steve was put in an isolated room on a drip. I had no clue what was wrong with him. Neither the nurses, nor the doctors nor Steve's family would tell me what was happening. As the next day unfolded everything became even stranger. I felt like everybody stopped talking when I walked into the room. It was like they were keeping something from me. At one point Steve's sister turned to me and said 'are you sure Steve has been taking all of his medication?' I was confused about what medication she was referring to.

20. Steve's brother turned up and asked to speak to Steve alone. When Steve's brother came out he looked really upset and agitated. He said 'Debs you need to go in there and ask Steve to tell you the truth'. I did not know what he was talking about. When I went in Steve looked like a rabbit caught in the headlights. He said 'they are all mad, they're all lying, don't listen to them'. I went back out to Steve's brother and explained what Steve had said. This happened 2 or 3 times, Steve's brother would go alone and then I would go in alone, but Steve was saying nothing to me.

21. I became very concerned, I asked Steve's brother 'is he dying and you don't want to tell me?' Steve's brother became visibly upset and his response was 'I can't believe we are making you think like that. Go in there and make him tell you the truth or I will'. His words stopped me in my tracks. I then went in one final time and Steve told me he had HIV. This conversation is a blur to me but I remember him saying the words 'HIV', 'contaminated blood', 'America', and 'the 80's'. I then vomited in the sink and I must have called out as nurses came running in the room. As soon as Steve told me I knew I had HIV too. My mind flashed back to the 18 months I had spent continuously ill, trying to find out what was wrong.

22. Shortly after I had to go and get a blood test to see if I had also been infected. As it was over Christmas I had to wait until the Monday for this test. I cannot remember the blood test on the Monday but at around 5pmish the same day I received the results. I remember a nurse telling me 'well, as you have already guessed its positive'. She put her hand on mine and said 'it's not the end of the world'. I was absolutely devastated and terrified and I felt like I wanted to punch her because it was the end of my world. I believe the nurse who told me could have handled it differently. You do not use a cliché in times like that.

23. I had a second blood test the next day as they wanted to check for any other infections. Dr GRO-B at Royal Liverpool Hospital was my HIV consultant for the next 15 months. He was Steve's HIV consultant as well. In the HIV clinic we waited about 3 hours for the second blood test. I was worried, upset and

worked myself up so much that when they finally went to take my blood I fainted. I don't remember much from the appointment other than the fact he asked me if I had a pension, I asked why and he said 'because you're going to need one'. I believe he was trying to say I was going to live long enough to need a pension but it did not sink in like that at the time.

24. I have attached to this statement marked Exhibit WITN1565002 a copy of a letter dated 31st December 2002 confirming my diagnosis with HIV.

25. I cannot remember what advice was given to me by the Royal Liverpool Hospital. I think the information was sufficient at the time even though I don't really remember it as I was traumatised. They knew a lot more about HIV at the time when I was diagnosed. They said people with HIV can live a long normal life. I remember them saying you could have children although at the time I did not believe them. I struggled to believe anyone about anything.

26. As I was still with Steve when I was diagnosed I think we would have been told that we still had to be careful if we had sex. We did not have sex for the 15 months after my diagnosis after which we broke up and so I did not take the information on board at the time. When Steve and I broke up I was not interested in any other relationship so I did not need information about staying safe. I already knew that condoms were needed to protect from STI's.

27. I moved my care to Chester Hospital after Steve and I broke up. Chester Hospital gave me advice on how to manage my infection and prevent others from getting infected.

Section 3. Other Infections

28. I do not believe I received any other infection.

Section 4. Consent

29. I do not believe I was tested or treated without my knowledge or consent.

Section 5. Impact of the Infection

30. I have suffered from chronic fatigue up until this day. I have stress, anxiety and depression. I think I am starting to develop Peripheral Neuropathy in my feet. I have had high cholesterol since I started on my medication for HIV. My cholesterol was always fine before then.

31. I have been told that it is very likely that I am suffering from Post Traumatic Stress Disorder, although this has not been formally diagnosed. I saw a psychiatrist in Manchester and he said I was showing signs of PTSD. I have recently seen a psychologist who suggested I was suffering from Dissociative Disorder (dissociation and depersonalisation). This is when nothing feels real. The people around you don't feel real. That's how it feels for me with my children. I have 3 children at home and it does not feel real. I have suffered symptoms on and off since my HIV diagnosis, mostly lasting for a few hours or a day or so. But since the Infected Blood Inquiry started my symptoms have exacerbated and I have been suffering from much more prolonged periods of dissociation, which have been terrifying. I have felt detached from reality and the world around me most days for several months now.

32. I was told in 2009 that the virus would probably decrease my life expectancy by about a decade. I try to not dwell on that possibility but it is something that has stayed with me.

33. I have always been sceptical of medication and I did not want to take medication if I did not need to. I did not need to take any medication when I was first diagnosed with HIV. I was aware when my levels started to drop as I was starting to get ill again and pick up bugs. The consultant at the hospital also told me that my levels were dropping and that I would need treatment for HIV. I was extremely reluctant and resistant to starting my HIV medication but realise that if I hadn't started when I did then I may not be alive today.

34. I have attached to this statement marked Exhibit WITN1565003 a copy of a letter from Chester Hospital dated 24 May 2007 which states that I needed to start triple therapy for HIV disease.

35. In December 2007 I started treatment for HIV. I have attached to this statement marked Exhibit WITN1565004 a document from Chester Hospital dated 2017 which sets out all the HIV treatment I have had since 2007 and some of the side effects I suffered with each treatment.

36. I was put on Kivexa and Efavirenz. I was made to understand that Kivexa can kill you within 24 hours if you're allergic; I did a test to check I was not allergic to the medication, but still had to have a friend stay over when I took it just in case. I broke out in a rash the next day and it made me panic. I think I contacted the clinic or A&E, however it turned out that it was not an allergic reaction. Efavirenz gave me nightmares, I became depressed and an insomniac. I adapted to the side effects like that was my new life. I was frightened of changing medication as I was not sure what new side effects I may develop if I did. I have attached to this statement marked Exhibit WITN1565005 a letter from Chester Hospital dated 1 April 2008 which sets out the difficulties I had with Efavirenz.

37. When I was pregnant in 2010 I had to change medication. I was taken on Efaverinz and put on Kaletra to take with the Kivexa. I had to take 2 Kaletra tablets twice a day. I suffered from chronic diarrhoea due to this medication. I had diarrhoea every day for 6 years. Again I was frightened to change medication because of the possibility of worse side effects.

38. I was extremely fatigued and stressed during my pregnancy. I started to forget to take my medication, and my viral load was creeping back up. I would set an alarm to try to remind myself but it did not work.

39. I was switched to a new medication called Triumeq very briefly. I only took the new medication for around a month as I became almost psychotic and felt like I was losing my mind. The hospital then switched me back to Kaletra.

40. After my third child was born in 2017 the doctors changed my medication to Genvoya, which is one tablet a day. I was given the impression that my consultants had to fight for this medication for me as it was more expensive. The side effects of Genvoya are constipation, fatigue and weight gain.

41. Fatigue has been a side effect of all the HIV medication I have taken. Fatigue is also a common symptom of HIV infection. Looking after three children would have been tiring enough, without having HIV. Being so fatigued makes it so much harder to be the mother I wanted to be.

42. I fear for the future because I don't know what damage the HIV medication is doing to my body. You can also become resistant to the medication. I try to not dwell on it but every time I have to take a tablet it is a reminder. Everyone says HIV is manageable but we do not know what these drugs are doing to us because they are all new. We are guinea pigs for these drugs. I have already developed high cholesterol since starting HIV medication. I don't know what they are doing to my liver, heart or kidneys. My doctors have offered me anti depressants but I do not want to take them.

43. The emotional impact has been drastic. When I found out Steve had HIV I was just in shock. I think I was screaming. When Steve said the word 'HIV' my mind just flew back to the tombstone adverts that I had seen in the 80s and the words 'don't die of ignorance'. I believed I would die. I stood at a window on the 7th floor of the hospital and thought of throwing myself out of it. It was 15 years later and knowledge and understanding had changed around HIV/AIDS but I didn't know this. I had had no reason to educate myself about it. I remained stuck with the belief that I was going to die and for a very long time I carried that with me all the time. Even though I know how 'fortunate' I am to have been diagnosed in 2002 and not in 1982, there is still some part of me that believes I am going to die from my HIV infection/AIDS.

44. I remember Steve's mum standing in front of me after Steve had told me about his HIV and saying to me 'but you're safe'. I remember screaming in her face

'No, I'm f***ing not! We have not been using condoms'. Steve's dad was there too and he just kept saying 'I thought you knew'. I believe Steve must have told his family I was safe.

45. I found out later that some time after Steve was told about his infection, he had told his parents that he never wanted to talk about it again, and that was what happened. His family never discussed it again. I remember asking Steve if he had ever worried his parents might slip up and that I would find out but he said 'I banked on them not saying anything'.

46. When I had my seroconversion in 1999, all of Steve's family knew I was ill. I do not know if they were aware that Steve had not told me about his HIV status. I want to think they were not 'in on it' and that they believed Steve had told me but I will never really know the truth about that. I have found out since that his sister had said to her husband in relation to my illness at the time 'you don't think this has anything to do with our Steve do you?' Yet, no one said anything.

47. Steve had so many opportunities to tell me about his HIV but he chose not to.

48. In the 1990s he received a sum of money which I now know came from the Macfarlane Trust (ex gratia payment). I knew Steve had savings but he told me that he had inherited some money from an uncle that really liked him.

49. I remember an occasion when my dad had a conversation with Steve about his Haemophilia. My dad knew somebody through his work whose twin sons died after being infected with HIV through FVIII. My dad had told Steve how lucky he was to have not caught anything and Steve just agreed with him.

50. In 2002 when Steve came out of hospital after having shingles he was sent home with medication. As someone who is not keen on taking medication I like to know what is what with medication and I always look up side effects etc. I looked Steve's medication up online and I was shocked to discover they were used for HIV. But the penny did not drop with regards to Steve's condition. I remember saying to Steve 'oh my God, the meds they have given you are used for HIV! Why do you think that is? Do you think it's because they are so

strong?' Steve's response was 'probably'. I have since felt ridiculous about my sheer ignorance but I really had no idea.

51. Steve made me look like a fool. I have trouble trusting people due to Steve's deceitful behaviour.

52. When Steve was admitted to hospital he had thirteen t-cells and my understanding is that he was dangerously sick with what used to be known as 'full blown AIDS'. He was dragged back from the brink of death during those 5 days in hospital. Because he was so ill, my own diagnosis faded into the background and I became preoccupied with looking after him. Despite finding out what he had done to me, I had a lot of compassion for how he had been infected as a child and I felt desperately sorry for him being so ill.

53. On New Years Day 2003, Steve and I left hospital and returned home to what would become our new normal for the next 15 months. But it was a world apart from the life we had for the previous 5 to 6 years. I felt like I no longer knew the man I lived with and in many respects it was like returning home with a complete stranger. I cannot actually remember much about the daily living that went on during that time. It is like those memories have been erased or are locked away somewhere in my mind. I do remember that I shouted and cried a lot. The only actual memory I have of Steve from that time is the way his face looked in hospital as he was getting more and more cornered into telling me the truth. It was a look that did not seem to leave him over the next 15 months and it is etched in my memory. Everything else is a blur.

54. I kept my infection from my parents and my brother for 3 months. I avoided phone calls and visits. That was difficult as we have always been a very close family. I did not tell anyone about my HIV status except one close friend. My parents were trying to pin me down because they knew something was going on. I phoned my brother one night and broke down asking him to come over. My brother wouldn't come over because he had commitments with his kids and he did not appreciate how serious it was. I then decided I would go to my

parents. I was on the motorway driving to my parent's house and I remember considering letting go of the wheel and letting the car smash.

55. I don't remember how I told my parents. It was the only time I have seen my dad cry. My mum phoned my brother and said 'Nigel get over here now'. They could not believe it. They were so angry. My mum was an auxiliary nurse so she knew that HIV did not mean what it used to mean. My dad did not know that though. My dad and my brother were freaked out by the news. My dad wanted to kill Steve and both of my parents wanted me to leave him.

56. I did not leave Steve. In spite of how they felt, my parents decided not to push me and to be there for me. They would come visit me regularly at the home I shared with Steve. It must have been very difficult for them to be sitting in the same house as Steve after what he had done to me.

57. I stayed with Steve for 15 months. Many people have asked me why I stayed. The simple answer is because I did not know what else to do. When you are thrown into a situation which I can only describe as hell - where you see no good choice - you pick the easiest. Staying was easier than leaving. He had two strokes after he was discharged from hospital and was still very ill. And I still loved him. I convinced myself that Steve must have been in denial for all those years or mentally ill because any other explanation for his deceit was unthinkable.

58. I had regular appointments for my HIV and I would get my blood taken at the HIV clinic with all the other individuals who had HIV from other causes. Steve had all his treatment at the Haematology Department and was able to hide behind this. He did not have to go to the HIV clinic like me and I resented this.

59. I cannot remember when it began exactly but I gradually started unravelling. I was struggling to get my head around what had happened in the hospital, finding out about Steve's HIV, my HIV, handling Steve's health as his condition became more complex, and trying to keep my supply teaching business going. I was overwhelmed with emotions including anger, fear, compassion, guilt,

depression and anxiety. I was beyond confused and I felt like life was continuing to drag me along with it, whether I liked it or not. I was also finding out more and more information from Steve and his family that made me question the idea that he had been in denial.

60. Steve kept me away from friends that knew he had HIV, he hid his drugs from me, and he had been going to all of his appointments alone. As time went on bits of information came out and I realised he could not have been in denial. As a computer analyst he used to work away for weeks at a time and often he would be away for the working week and back home for the weekends. One day I came across a big sports bag in our loft which was full of boxes of medication. I confronted him about this and he told me that he used to take his HIV medication when he was away on contract but would stop taking them as soon as he returned home. The fact that he took his medication when he was away made it clear to me that his deceit was, at least to some degree, deliberate.

61. If Steve had taken his HIV medication as prescribed I would probably have been protected, even without using condoms. By stopping and starting his medication the way he did, he increased the odds of me contracting the virus from him because the HIV was no longer suppressed and his viral load spiked.

62. The more I found out the more horrified I became. But it still felt like I was trapped in a shocked trance.

63. The relationship ended on the silliest thing. In March 2004 we were planning to go on a respite break with the help of the Macfarlane Trust, we had found a cheap cruise to the Caribbean which we decided to go on. I had to go and get a yellow fever jab to be able to go and when I went to the GP he said 'you cannot have a live virus vaccination as you have HIV'. It was at that moment that it clicked that my life had changed forever. It absolutely broke me. I drove back home and asked Steve to move out immediately to his parents. I told him I needed space and time to think. Steve moved out and other than one instance

when he turned up outside the house uninvited (I saw him through the car window), I never saw him again.

64. It was only when I broke up with Steve that I started to deal with what had happened to me. I was exhausted and mentally wrecked. Steve was also harassing me - phoning, sending flowers, etc. It took me phoning his sister and threatening to call the police for an injunction to make him stop. I went on holiday to Greece in August and then I decided to move there to live. I sold everything and moved to Corfu, Greece in October 2004. The Macfarlane Trust helped me ship everything I wanted to move. I ran away from it all.

65. I found myself a house in the mountains and at first did not tell anyone about my infection. I lived off money from the Macfarlane Trust and my bank overdraft while looking for a job. I eventually found a job at the private village school working part time.

66. While in Greece, I checked my bank balance one day and £10,000 had been deposited into my account by Steve. He had received his HCV ex-gratia pay-out and he gave half to me. I did not contact him but I was in a huge amount of debt and desperate so I just accepted the money.

67. When I was living in Greece I had two friends who I told about my infected status, one male and one female. I had been working at the school for a few months when I received a phone call from one of the bosses saying they needed to speak to me. My female friend had told her husband about my HIV status and he thought I should not be working with children and informed the school. He told the school that if they did not get rid of me he would tell the whole village that I had HIV. The school ended my employment but he told the village about me anyway. I was distraught and I hid away in my home for 3 months after this. I sank into a deep depression. During this period my other friend bought food cooked by his mother every day to my apartment.

68. After this I went back to the UK for a bit to decide what to do next. My dad had been diagnosed with prostate cancer and I thought about moving back home to

England permanently. I decided to stay in Greece and face things. I decided to be open with people about my HIV status and they could either handle it or not. I started offering private tuition and before accepting any job I would tell the parents that I had HIV and they would then decide if they still wanted to hire me. Some of them did and some of them didn't. It was frightening and humiliating but I felt I had no other choice if I was going to stay in Corfu.

69. I had sex with my male friend in Greece and he would shower profusely straight after. It made me feel awful. I used to cry in the other room while he scrubbed himself from head to toe. At the time I was grateful anyone wanted to come near me. It was not a relationship though, he never even kissed me. It was yet another distressing and humiliating experience for me. It took me a long time to find the courage to end this toxic aspect of the friendship.

70. My dad got sicker and I felt lonely in Greece as I had no social life. I had also gotten to the point where my HIV needed treatment. I refer to the letter marked Exhibit WITN1565003 which sets out some of the issues I faced at the time. I decided to come back to the UK and moved back in July 2007. I returned to one of the schools I used to teach at and told the head teacher all about my HIV infection and asked if he would still employee me. He said yes as long as I was not a first aider.

71. I was single for 5 years after I broke up with Steve. I did not want to be in another relationship. I spent all those years alone because it was easier than having to put my trust in someone again. The experience with my male Greek friend added to my insecurities about my HIV and exacerbated my trust issues.

72. My dad passed away on GRO-C 2009 and just prior to his death he made me promise I would get back out there to try to meet someone.

73. I kept my promise to my dad and in April 2009 I ended up meeting my partner Neil on an online dating chatroom. I had to take a leap of faith, but because of what I went through with Steve, I have not been able to trust Neil. This has caused huge issues for us as a couple and has put immense strain on our

relationship. I feel cheated out of the life I should have had. My life feels almost like a ghost of a life.

74. I got involved with Neil without any trust. We have been through periods where I have been checking his phone to check if he is hiding anything. GRO-C GRO-C Neil was a condemned man before he even started. This has gone on for years.

75. Neil has been amazing really. He has ridden the roller coaster ride with me. He has been supportive but he has limits and his own issues. From the word go as a couple it was not normal for us. From the beginning we had to navigate our sex life. GRO-C he agreed to meet my HIV consultant. My attitude towards sex has never been the same since my diagnosis. I disclosed on my dating profile that I had HIV so Neil knew from the start. He said he wrote to me for friendship but when we actually met in real life we simply hit it off. Neil made it his mission to educate himself about HIV. He worries a lot more about my mental health than the actual HIV infection.

76. HIV lives with me every moment of every day. It has tainted everything. It has tainted my experience of being a mother and having a new relationship. I don't trust anybody. I have lost so much time with my children, time I am never going to get back.

77. I have had a lot of pregnancy losses. I think this is due to my age. I spent my younger years with Steve and when we broke up I was 32 and I was in a frame of mind then that I wouldn't, couldn't and shouldn't have children. I never went down that road because I did not have a partner and I was HIV positive. I did not think it was responsible for me to do so. I thought maybe I would adopt a child with HIV. By the time I finally came to having children I was older.

78. The first time I got pregnant it was an accident. Neil and I always used condoms. Neil had met my consultant and knew all my background. We were very drunk in the Lake District one night and did not use a condom and I fell

pregnant. Neil said when we saw the pregnancy test result he could see in my eyes that a baby was what I wanted. Neil had a teenage daughter at the time GRO-C GRO-C. Sadly, I lost my baby at the 12 week mark, in September 2010.

79. GRO-C we decided to try for another baby. My viral load was undetectable at this time and we were told it was safe to try naturally for a child. I was however frightened of passing HIV to Neil, so we tried for a baby using a syringe to put Neil's sperm into me.

80. I got pregnant again but when we got to the 20 week scan they found out our baby had Edwards Syndrome. They did further tests and we were told she would die when she was born. I had to terminate the pregnancy. She would have been 8 years old now if she had survived. This was possibly the worst time in my life, where I seriously considered giving up and committing suicide. Neil has told me he thought he was going to lose me during the months that followed. It was a very dark time for me and the lowest I have ever been.

81. For the next 7 months we kept trying to conceive again. I have read that HIV can make it more difficult to conceive. Finally after 7 months I was pregnant again. Throughout the pregnancy it was a nightmare because I was frightened the whole time. As well as the usual pregnancy exhaustion, I was frightened I would miscarry, or that something would go wrong and I'd be forced to have a termination again, or that the baby would be HIV positive.

82. My son was born GRO-C I felt horrendously guilty GRO-C for the first four weeks of his life. I was frightened GRO-C GRO-C. We had to feed GRO-C him through his bottle teat, then quickly give him his bottle afterwards. That was another devastating thing for me. Being HIV positive meant I couldn't breastfeed. It has always saddened me. I was told that it would be 18 months before they could be 100% sure that he did not have HIV. I spent those 18 months feeling frightened and guilty. I collapsed on the floor when I received the phone call from the doctor GRO-C

GRO-C I have been through this three times with each of our sons. Worry, fear and guilt were my 'post-natal depression', three times over.

83. I had another 2 miscarriages after my first child was born but then I went on to have another 2 children.

84. When I was pregnant with my second child the harmony test had been created and it could show if there were any HIV chromosomes in the baby. This is not offered on the NHS and costs around £600. I applied to the Macfarlane Trust and I had to fight for them to cover the cost, which they did. When I was pregnant with my third child the Macfarlane Trust refused to pay for the harmony test so Neil and I had to self fund it. GRO-C GRO-C

85. When we were trying for children Neil had more faith than me that our children would be HIV negative but he confessed to me later that there was always that little voice of doubt telling him the baby may be infected. We both wanted and needed that piece of paper telling us GRO-C.

86. There is a massive impact on the children because I'm emotionally and mentally volatile. I am often too tired to play and interact the way I would have liked to. I get irritable and impatient. I am a gentle parent by nature and when I feel ok I am the parent I want to be, but it doesn't last. The way I am with them breaks my heart because it is the opposite of how I want to be. Since 2016 my anxiety and depression have returned with a vengeance and I am angry most of the time. Since the Inquiry started my anger has got even worse. My children ask why I am crying all the time and I don't know what to say to them.

87. I am going to have to tell my children some day that I am HIV positive. I don't look forward to this. I don't know what I am going to say to them. I am hoping I can explain why I was missing 'emotionally' for such a large chunk of their younger lives. I have been involved with Tainted Blood and the 'campaign' since April 2016. As well as the terrible emotional impact it has had on me being involved has taken up a huge amount of my time.

Following social media (afraid I'll miss something important), talking and meeting with other campaigners, writing emails to and meeting with my MP, going to debates and meetings in London, talking with reporters, following the Inquiry - this all takes up time I don't have to spare as a full time mother. I've had to rely on Neil a lot to take over and hold the fort. Both he and our children have often been on the receiving end of my anger and frustration as I've desperately tried to keep doing everything and balance everything, all the while also battling with daily fatigue, anxiety and depression. I feel guilty for not being fully here and available for my children as much as I could have been but I have felt and still feel compelled to be involved in campaign work and the Inquiry until it is over. I also feel guilty for my outbursts of sadness, impatience, frustration and anger they've all had to witness at such a young age. I can only hope when they're older that they will understand what I was going through and that they will be supportive and proud of me for not giving up.

88. People look at me and think I have a beautiful life because I have a lovely house, 3 children and I don't work. But I feel I have lost so much. I will never get those years back with my children. I am grateful I have had children as I have friends who haven't but sometimes I feel just as bad for having them and not being able to be there for them properly.

89. When I am at my worst I just want to walk away from it all because I think they would be better off without me. I was such a different person before I was diagnosed with HIV. I was so positive and stress did not touch me but the last 16 years have crippled me. The recent events with the Infected Blood Inquiry have just battered me back down again. The last three years have ripped open old wounds and it's like an emotional Pandora's Box has been unleashed.

90. There is still a lot of stigma surrounding HIV. I have a fear of stigma at the back of my mind. Every time you tell someone about your HIV status it is worrying. If people don't get in touch with you, you think it is because you have HIV. I have had a couple of friendships break up and I question if it is because I have HIV.

You take a gamble every time you tell someone. It's not just my own security anymore, it is my children as well

91. I set up my own business as a supply teacher (sole trader) in Spring 2000, before I found out that I had HIV. I loved it. I set my fees lower than other agencies and I had a lot of business, I was never short of work. I had 200 schools on my books and I also provided private tutoring. When I set up my business I thought of eventually extending it to an agency. Unfortunately it started falling apart when I got sick. I lost out financially from not being able to work and I was lost clients as I was too sick to work.

92. I tried to continue working after Steve's hospitalisation in December 2002 and my HIV diagnosis, but I was Steve's full time carer which made it difficult to continue working and I eventually had to give up work.

93. Other than one short contract (according to my MFT notes) Steve did not work again throughout the remainder of our relationship. He went from being a computer analyst earning on average about £70,000 a year to relying on state benefits. We both went from working full time earning two very good incomes to relying on state benefits and the support payments from the Macfarlane Trust, which at the time were pittance (a few hundred pounds a month).

94. Having HIV destroyed my business and my career. My mental health suffered so much that I was no longer able to function in the same way. I have suffered from anxiety and depression ever since finding out about my infection and have never been able to recover fully. I make progress only to slide again; I start to unravel all over again when things get hard.

95. I have not worked for the last 10 years because of a combination of HIV, difficult high risk pregnancies and side effects from the HIV treatment. It is embarrassing to admit that you have not worked for 10 years.

96. I have had to jump through hoops with the benefit system. I have to fight for ESA every time they try to change the amount of money I receive. For disability

allowance they don't accept mental health as being relevant. I have been through the ridiculous, humiliating tests with the benefits assessments. This does not help with my depression or my self-esteem.

97. GRO-C

98. I was only able to get a mortgage because GRO-C agreed to be my guarantor. Only one lender agreed to give me a mortgage, on the condition that I had a guarantor. Everywhere else I applied, I was refused due to my HIV infection. I was very fortunate that GRO-C agreed to do this for me. I have never bothered trying to get life insurance because I did want not go through the humiliation of being rejected.

99. I was involved in a police case against Steve. When I was in Greece I started talking to people with HIV in a forum called AIDSmeds. As I got more informed, I started realising the extent of what Steve had done and that what he had done was possibly criminal. I feared he was out there infecting other people. My feelings have changed over the years but at that time I was angry at him for ruining my life. I went to the local police and a case was started against Steve. The police also told me that I was eligible to submit a claim to the Criminal Injuries Compensation Authority (CICA) which I did.

100. The police case took 5 years and even though they knew Steve infected me the case was dropped in 2012 because one person I had a protected one night stand with before I met Steve could not be located. In the long run I am relieved it was dropped because I was pregnant and stressed at the time.

101. With regard to the CICA claim, I received an interim payment of £16,000 and then, all of a sudden, it was like they changed their minds and they tried blaming me saying I had not protected myself and also that I had stayed with Steve for a long time after I found out that I had HIV. I found a solicitor in Bolton who took it to appeal. It took another 3 and a half years but I won the appeal.

102. I have attached to this statement marked Exhibit WITN1565006 a letter which my consultant wrote to the CICA in April 2010 in order to try and help me with the claim. Even though I was the victim, I was made to feel both in relation to the police case and the CICA claim that I was to blame for what had happened to me.

103. When I started discussing the possibility of prosecuting Steve on the AIDSmeds Forum, I came against opposition from the homosexual HIV community. You get a lot of people in the HIV community who are worried people could go to the police out of revenge when they want to pass the buck. They would say I should have been using protection but for a heterosexual couple it has to come to a point where you trust each other. I did not feel like I belonged in the HIV community.

104. When it came to the Haemophilia community I did not feel like I belonged there either because it was one of them who gave HIV to me. It felt like I was the enemy instead of a victim. I had a haemophiliac say to me 'you're putting us in a bad light' when I went public. A lot of my haemophiliac friends have since reassured me and said to me that they believe Steve betrayed them as a community. They have said to me that I had a double hit. I am dealing with what Steve did to me and with what the government/health service did to him.

105. I believe Steve was not an evil person but he was very messed up by what had happened to him and he was also a coward. I have a conflict of emotions between what has happened to me and what happened to Steve and this stops me from moving on. I have spent many years consumed with anger towards him but I also have a huge amount of compassion for how he was infected and what it must have been like for him being diagnosed in the 90s. Therapists

have told me that this is stopping me being able to fully process my own emotions over what Steve did to me and my HIV diagnosis.

106. I received a letter in 2016 stating that the Department of Health were thinking of cutting our Macfarlane Trust discretionary payments; I had a family so it is worrying when they say they might cut my money. I was livid. My reaction was to go to the papers. I was so angry that I phoned The Independent and said I had a story for them. I also went to the local papers.

107. This started off the nightmare that these last three years have been. During this period I joined Tainted Blood and attended a debate and protest in London, where I met other people infected and affected by the Contaminated Blood Scandal. I also found out that that Steve had died in GRO-C 2016 – I saw his obituary and I know I still haven't fully processed this. I feel that in the course of the last three years every wound that I have ever had has been ripped open. When I have seen or heard anything about the Inquiry I have ended up angry or crying. I feel like I have been left hanging, I just want it over.

Section 6. Treatment/care/support

108. I have not been refused treatment by any medical establishment as a result of my HIV infection.

109. In Greece I was left until the end of the day at dentist appointments but in the UK I don't think having HIV has affected my health or dental care.

110. During one of my miscarriages I was admitted to the Chester Hospital Maternity Unit. My partner Neil was very angry when he saw that a sticker saying 'biohazard' had been put on the outside of my door.

111. I had some counselling with Steve but I stopped it as I felt that the therapist was on Steve's side.

112. I first received counselling through Sahir House in Liverpool. I also received counselling from Body Positive through Chester Hospital. I became aware of it as someone from Body Positive came into the HIV clinic that I attended. I have been having talk therapy since I was diagnosed with HIV, including Cognitive Behaviour Therapy (CBT).

113. I started Eye Movement Desensitization and Reprocessing (EMDR) psychotherapy earlier this year (March 2019) and it messed me up even more. It made everything seem worse and not real. After looking into it I discovered that EMDR should not be carried out in its standard form with clients who suffer from Dissociative Disorder. I have fallen apart again because nothing seems real around me.

114. I think there should have been more provision for mental support from the trusts. There should be no restrictions on counselling. I have had free counselling but the NHS only do a certain number of sessions and Body Positive only have trainees. Since doing my statement I have found out that Body Positive no longer provide counselling for HIV clients, due to funding cuts. When I was looking at more specialist therapy the Macfarlane Trust would not fund it and the NHS would add you to a massive waiting list. I did not have time to wait as I was falling apart. I am currently waiting to see another psychologist, that has been arranged through my HIV clinic.

115. It is good that the Inquiry has set up the Red Cross to support us through this tough time but for a lot of people it is too little too late. The people that were supposed to support us should have been more available and you should not have to pay for support needed.

116. Recently I have had to pay for counselling.

Section 7. Financial Assistance

117. I found out about the Macfarlane Trust through Steve's family in around 2003. Steve had received payments from them, and I was entitled to payments as

well. I did not know Steve had received these payments before because they went into his bank account.

118. I applied to the Macfarlane Trust and they made payments to me which they back dated to the date I was diagnosed with HIV. The money was very little at the time. It did not mean that much to me because I was in shock. I would have said okay to anything. I just felt grateful I was getting some money.

119. The fact that the Macfarlane Trust was paying out money was all very innocent to me at the time. I did not fully appreciate at the time the scale of what had happened with the use of infected blood and blood products. It has only been in the last 3 years that I questioned if they should have been doing things the way they were.

120. The Macfarlane Trust helped me move to Greece and they helped me to move back to the UK. They also paid for me to come back to the UK 3 to 4 times a year to attend the HIV clinic at Chester and be checked out. They were generous with me.

121. In the last few years I have felt like I have had to jump through hoops to get anything. The application process has changed and not for the better.

122. In 2006 I applied for a grant in order to have a respite break with family in Australia. I was at the time going through significant stress and anxiety – this was within a year of my experience of significant stigma in Greece, due to my HIV infection. I was turned down even though I had provided three separate medical recommendation letters to support my application. I have attached to this statement marked Exhibit WITN1565007 copy emails with the MacFarlane Trust, in which they declined my request on the basis that they did not consider my request to be exceptional because I was not hospitalised or bed-ridden. One of the emails refers to my request as being 'a touch extravagant for a "break"'.

123. You are only able to get grants from the Macfarlane Trust if you can link it to HIV. I needed to have a window replaced and I had to go to the consultant to show why it would affect my HIV. I have had to show a link to my HIV for everything I have applied to from the Trust.

124. When I needed repairs to my patio, I put an application for this. They paid half the cost and gave me a loan for the rest. They took the loan repayments directly out of my payments for the next two years.

125. The Trust expects you to get invoices and prices from a few different companies to support all applications. You need a headed invoice. It is humiliating asking for this, I don't want to have to tell my business to people fixing my pipes. I believe the process should be easier, you should not have to keep going to them cap in hand.

126. In 2016 I found out that when I became an MFT beneficiary in 2003 I should have received an ex-gratia payment of £23,500 which was paid out to all HIV infected partners. I was not informed of this. I went to the Macfarlane trust and asked them about it but it took 6 months to receive the payment. After I received the lump sum payment the Macfarlane Trust used it as a reason to refuse some of my subsequent applications, asking me what I had spent the lump sum on. They would not pay me the interest I could have made on that money either.

127. I have attached to this statement marked Exhibit WITN1565008 a copy of an email I received from the Macfarlane Trust on 17 February 2017 in which they refused to allow the cost of a pre natal scan because they believed I had sufficient funds to pay for this myself. The email suggested that I consider being referred to their money management advisers to help me with my budgeting and money management!

128. Up until July 2019 I was receiving £18,000 annually and a discretionary top up payment of £695 per month, which made for a total of £26,340 per year. My annual payment has now been increased to £28,000 annually plus monthly

means-tested child payments of £450. But they have removed the top up allowance. So, numbers have just been shuffled around to some degree. I now receive £33,400 a year, meaning just over £7000 increase. It sounds a lot but it really isn't over a year, especially considering what I could have been earning with my supply teaching business. Not to mention the fact that this increase was announced on the first day of the Inquiry; I believe it was a tactical move, deliberately left until the last moment in an attempt to distract from the Inquiry.

129. The Trust has now changed to EIBISS and things have been worse since then. There is no longer any personal contact and I feel that I am just a number. I am also known within the system as an 'infected intimate', which is a term that HIV infected partners have found insulting for years and many wish for the term to be removed.

130. I think it's disgusting that any element of payments should be means tested for sick people. They are supposed to be making it easier but you're forced to jump through hoops.

131. The payments are also very uneven, both ongoing and lump sum payments. It's like it has been done in a way to make us all fight amongst each other. There is no logic to how payments are made across the UK and the various groups (HIV and HCV infected). These inequalities need addressing.

132. When I filed a complaint against Steve, the police told me that I was eligible to submit a claim to the Criminal Injuries Compensation Authority (CICA). I did so and initially, I received an interim payment of £16,000. Then, all of a sudden, it was like they changed their minds and they tried blaming me saying I had not protected myself. I found a solicitor in Bolton who took it to appeal. It took another 3 and a half years but I won the appeal. I received around £135,000. The lawyer took a percentage; I think the ruling was for about £170,000. The money from the CICA enabled me to buy my home.

133. It should not come down to money but my life has been battered down because of my HIV infection and I struggle financially. Every quarter I'm £2,000

in overdraft because I cannot catch up with my payments. Also relying on benefits is humiliating. It is hard to not think about money. Neil is trying to set his business up but if Neil was out working I would be left on my own. I would not be able to manage everything - our children and home - on my own.

Section 8. Other Issues

134. I hope that the Inquiry gets the dirty truth out that has been hidden for all these years by the government and pharmaceutical companies. They have hidden it year after year and government after government. I hope for Steve's family and all the haemophilia boys that they get the truth they deserve.

135. The government and pharmaceutical companies need to be held to account for what they did. Just like we would be if we did something wrong.

136. Everyone affected should be looked after and everyone's individual needs – financial and emotional – should be addressed.

137. From a personal point of view I want my financial security back. I don't want to be begging for a grant to fix my radiator. I don't want to be waiting to see what they will take next. I don't know what the future holds for me. My HIV infection hangs over me like Damocle's Sword. My biggest fear is I won't be around to see my children grow up and have their own families. I don't want my children to be fighting this fight in decades to come. It has to end. I would like to get some sense of peace and to be left alone to get on with my life.

138. My story is so different to everybody else's. Most HIV infected partners don't come forward because they are still scared of stigma and discrimination. I am worried we are going to be forgotten. I don't feel like I belong anywhere.

139. The life I had all those years ago just seems like a distant memory. I am very thankful for Neil and my children but I am so angry I am not able to enjoy motherhood and family life to the degree I should. This Inquiry should have happened years ago. It is too late for so many people. The last 3 years have

ripped all my wounds open when I thought I had sealed them shut. I need this ordeal to be over so I can try to heal and move on properly. I need closure.

Anonymity, disclosure and redaction

140. I am not seeking anonymity. I understand this statement will be published and disclosed as part of the Inquiry.

141. I wish 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 20 · 8 · 19