Witness Name: Emma Jayne Hughes
Statement No: WITN4110001
Exhibits: 0
Dated: March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF EMMA JAYNE HUGHES

I, Emma Jayne Hughes, will say as follows:-

Section 1. Introduction

1. My name is Emma Jayne Hughes. I was born on GRO-C 1973 and I live at GRO-C Worcestershire GRO-C. I live here with Stuart, my partner of 25 years, and our children GRO-C (aged 12), GRO-C (aged 9) and GRO-C (aged 4).

2. My partner, Stuart Gregg (born on GRO-C 1975), was co-infected with the Hepatitis B Virus (HBV), the Hepatitis C Virus (HCV) and the Human Immunodeficiency Virus (HIV) through contaminated Factor VIII (FVIII) blood products. Stuart has provided his own Witness Statement to the Inquiry (Witness Statement Number WITN1252001).

Section 2. How Affected

3. Stuart has severe Haemophilia A, diagnosed at approximately 18 months. As a child, Stuart was treated at the Birmingham Children's Hospital (BCH) under

the care of Dr Frank Hill. Stuart was then treated from 1994 at the Queen Elizabeth Hospital, Birmingham (QEH) under Dr Jonathan Wilde.

4. Stuart was infected with HIV in or around 1984. His treatment at that time was Factorate made by the Armour Pharmaceutical Company. Stuart's positive HIV diagnosis became apparent to him over time and many years later. He was never sat down and told face to face.

5. Stuart was infected with hepatitis before being infected with HIV but was not aware of the HCV diagnosis until around the late 1990s/early 2000s. Again he was never sat down and told face to face.

6. Stuart's parents were not told about the risk of infection through FVIII blood products before Stuart was given the treatment. Stuart's mother was repeatedly assured FVIII concentrate was safe and that they should keep using it. She was also told by an Armour products representative at a Haemophilia Conference in the mid 1980s that their products were 'completely safe'.

7. Very little information was provided to Stuart about understanding and managing his infections. Stuart and I were very careful not to have unprotected sex. Stuart was always quick and very careful about cleaning up blood spillages albeit I think that that was drummed into him by his mother.

8. No information was provided to me in order to understand and manage Stuart's infections (as detailed at paragraphs 18 and 19 below).

Section 3. Other Infections

9. Stuart has been informed that he was exposed to the risk of vCJD.

10. Whilst in hospital as a child, Stuart contracted TB through being exposed to another patient with TB.

Section 4. Consent

11. Stuart was treated and tested without his knowledge and consent and without the knowledge and consent of his parents.

12. Stuart believes that he was used as the subject of research. Stuart has exhibited to his own Statement a copy letter dated 11th January 1982 from Dr Bloom and Dr Rizza to all other UK Centre Directors suggesting patients not previously exposed to large pool concentrates as ideal research candidates. Stuart was given FVIII on a regular basis over a long period of time after the said letter was sent and without ever having had a life-threatening bleed which necessitated treatment.

Section 5. Impact of the Infection

13. Stuart and I went to the same secondary school. I knew of Stuart and I knew that he had haemophilia but we, the pupils, didn't really understand what that was. Stuart and I met again in 1995 through a friend at a pub. I was 21 and Stuart was 20.

14. The fact that Stuart was a haemophiliac never presented as a problem to me. We went out on dates and we grew fond of each other. One Sunday Stuart told me that he had HIV, infected through contaminated blood in 1984, aged 9. I may have been naïve but I don't remember being particularly shocked. I had grown to like him too much to walk away, I cared for Stuart and I did not see that this situation would come between us. I was of course shocked and saddened that such a thing had happened to him, as a child, and that it had been brushed under the carpet. I couldn't fathom how this could have happened to Stuart and so many other haemophiliacs. I personally felt how stigma was associated with HIV and I made a conscious decision not to tell any family or friends. I felt that I didn't want to worry or burden my father with this information, especially as an understanding of HIV in his generation was not that prevalent. This would then subsequently leave me feel very alone with my feelings and worries for Stuart.

15. Stuart was told, as a teenager, that he wouldn't live that long and this had a subsequent impact on his approach to his education. Stuart had taken A' levels but hadn't been focused academically because he didn't think there was any point with not having a long term future. At age 18 Stuart had gone to University for a brief time but had dropped out by the end of the first year. He was living independently in his own flat from the age of 19. I met Stuart's parents and sister and they were very protective of him. When he told me that he had HIV, that protective nature made sense.

16. Almost as soon as Stuart told me that he had HIV, I made the decision not to tell anyone, not even my own family. My parents had me in their forties and I didn't think they would understand. I didn't want to worry them, or my sister or my friends. I was worried about the reaction of other people because of the associated stigma. There had been advertisements on TV about AIDS and people with HIV and AIDS had been treated badly. That decision placed me under enormous pressure, leaving me without support at times in my life when I really needed it. It has been lonely and isolating for me. When you find yourself in this situation you just take things day by day and try to get on with life as best you can.

17. Stuart did not really have any proper understanding of his Hepatitis status or that he specifically had HBV and HCV. This didn't become a realisation, nor an issue, until much later. I do however recall him suffering with his health and fatigue even back in the early days of when we met.

18. I want to mention a pertinent situation that occurred in the early days of our relationship. During intercourse a condom split, neither Stuart or I knew what to do or where to turn. The only person I could speak to for advice was Stuart's mother (this was awkward for me to have to do being in my early twenties). She advised us to go up to the Haemophilia Centre, they prescribed the morning after pill and took my blood to test for HIV. No one offered me any support and it wasn't really talked through with me in any way. I naturally presumed that I too was now infected. In those days our knowledge

(and that of the medical profession) was not that great and any kind of exposure was anticipated would lead to transmission of HIV. For the two weeks or so following my test I had a brief insight into Stuart's life and I realised that this was his reality. I was terrified and scared about the fact I would be infected with HIV. It was a difficult time and I couldn't talk to anyone about this. I remember going to work in a daze. It felt that my head was wrapped in cotton wool and that I had no one I could to talk to about it. Luckily, as it turned out, the result was negative, but it was a very traumatic experience overall.

19. I sometimes went with Stuart to his appointments at the QEH and saw Dr Wilde. No information, literature or counselling was ever offered or provided to me in regards to being the partner of an infected individual. We were just told to take precautions and not have unprotected sex. Stuart went back to University in 1998 at the age of 23. Alongside his undergraduate work he undertook voluntary work at a local HIV Centre, he became involved in committees, he then studied and researched HIV further in both his MA and PhD and even used this knowledge on the subject when giving lectures at the University. By 2006 the commute to and from Birmingham became too much for Stuart in terms of his health. Stuart's wealth of knowledge on the subject of HIV has been gained through his own efforts, researching and networks, rather than ever being offered information and research through healthcare providers.

20. Stuart's health deteriorated over a period of time and by the time Stuart was 21/22, circa 1997, his health started to worsen and was ill. His CD4 count was down to just 10, which was not a good indicator. He was also debilitated with some bad bleeds during this time. I was really worried then about us having any form of long term future together. Dr Wilde put Stuart on to his first proper regime of antiretroviral drugs in January 1997. The drug regime was pernicious, with severe side effects such as nausea and fatigue, which exacerbated his symptoms and overall feeling of ill-health. As an aside, I would mention that I have never understood why Dr Wilde (a Haemophilia

Consultant) had the responsibility for treating patients with HIV. Stuart now has his own HIV Consultant in Worcester.

21. Stuart had an inkling that he had HCV in addition to HIV, however as the HIV took such a devastating presence the Hepatitis was never really discussed and he wasn't truly aware of his Hepatitis status. Stuart had been told at hospital that he was antigen positive, but wasn't sure what that meant. He was aware that other people were co-infected, but in the early days his knowledge and understanding of what this meant was just not there. Stuart knew that he had been exposed to contaminated blood and that no real information or explanation was forthcoming, just that he knew he would die shortly from this. Furthermore during his childhood he was exposed to TB and became very ill, which has had a long term impact and exacerbated his overall state of health. No one ever sat us down to inform us that Stuart had HCV and talk about our options. Instead we were drip fed the information and no concrete discussions took place about Hepatitis treatment until around 2009.

22. I lost my father in 2002 and his death had a huge impact on me and my relationship with Stuart. We had been living on a day to day basis and weren't able to plan for the future or think about starting a family. I was unable to share what Stuart and I were battling with and going through with other close family and friends. The cracks in our relationship started to show and we spent a few months apart but we were strong and we wanted to stay together.

23. Due to Stuart's poor health and inability to have inoculations we never travelled far together. However, we were able to take a holiday to Florida for the family occasion when Stuart's sister got married. Stuart declared his HIV status and obtained a special visa to enter the USA. We were nevertheless taken into a separate room at border control to be questioned. We felt discriminated against, laid bare to explain Stuart's HIV and haemophilia medication and how he had come to be infected. It was a horrible experience.

24. I didn't think it was possible for us to become parents, but, as we reached our thirties, I knew with certainty that I wanted a family. Stuart's viral load was undetectable but unprotected sex to start a family was still not encouraged at this time in the mid 2000s. Through his studies, Stuart had become knowledgeable about what options where available to us – these included natural conception and various forms of assisted conception, including spermwashing. Dr Wilde had written a good research paper around that time discussing natural conception in serodiscordant couples. However, at that time I was uncomfortable and nervous with natural conception and was honestly scared about the risk involved. Ultimately, we found that there was a relatively new spermwashing/IVF process available then at the Chelsea and Westminster Hospital, London. I was classed as infertile from the very start of entering the assisted conception unit, and given lots of tests, even though our reasons for entering into assisted conception were completely different to most other people and were certainly not due to fertility issues.

25. In order to get a referral to have the assisted conception treatment I had to disclose everything to my GP. I had to go to Birmingham Women's Hospital for tests to ensure that I was ovulating. The medical staff there were not at all warm or supportive towards our predicament. The MacFarlane Trust gave us some money towards the first cycle of IVF and we had to pay the subsequent cycles. It actually took two and a half years of overcoming obstacles for us to get to that part of the treatment process; many years of travelling to and from London, trying to work full time around appointments without being able to explain to my employer what I was doing. Nor was I able to get any support from my family or friends again throughout this very difficult process.

26. Our IUI cycle was unsuccessful and we were moved straight onto an ICSI programme (Intracytoplasmic Sperm Injection) – due to the loss of sperm during the washing process in IUI. From the ICSI cycle we were able to harvest at least 12 embryos, from which our eldest daughter was conceived after the first cycle. Sadly, because there was no freezing facility at the hospital, for co-infected patients, all the viable embryos remaining had to be

destroyed. I didn't consider the terrible ramifications of this at the time; I had to accept it as we had no choice.

27. A number of years later the Chelsea and Westminster Hospital were able to provide freezing facility for the embryos of co-infected patients.

28. When I had my daughter, I felt absolute joy. We felt so lucky because we never thought we were going to have children. I wanted another child and a sibling for my daughter. We then self-funded several rounds of IVF at great expense, in total we have paid approx £20,000 to create our family, when both of us were fertile and were trying to do the right thing by ensuring there was no HIV transmission, but it came at great financial hardship to us. I was at a very low ebb when trying to conceive our second child. The whole process took a huge toll on me; the rigours of the drugs, the endless egg collections and the cycles. My body could not have done any more. I was drained physically and emotionally. I went through the entire fertility process without telling friends and family what I was doing. To this day, my sister still doesn't know what I battled through to create my family. I felt depressed and I would often sit and cry because I had bottled everything up for so long. On reflection I can identify that the whole process was very demanding, demoralising and took a lot out of me and I was depressed. It took time for me to do it but I was able to work my way out of the situation. I was left having to battle through everything alone and it felt that no-one knew or understood what we had gone through or that I had nobody there to support us through those hard times.

29. Stuart had planned to undergo a course of HCV treatment to try and eradicate Hepatitis C. This HCV treatment had to be delayed initially due to us undergoing fertility treatment, this was because Interferon and Ribavarin are known to cause birth defects, also Stuart needed to change his antiretroviral HIV drugs for his HCV treatment but couldn't do that whilst undertaking assisted conception as it could compromise his viral load. Luckily the assisted conception was finally successful and Stuart then started the HCV treatment whilst I was pregnant and our second child was born when he was 6 months

into the treatment. Very early on Stuart found the HCV treatment drug regime to be very hard to tolerate. He endured many terrible side effects which included nausea, weight loss, brain fog, depression etc . He looked gaunt and haunted, I watched the life seep out of him. He couldn't think clearly or make decisions and his life was wasting away right in front of me. The mood swings were the most difficult thing for me to contend with, especially with having a young family. Stuart could quickly become angry and upset and would walk away from the rest of the household. It was the worst time of his life, the HCV drugs broke his spirit and the fight in him that had hitherto been ever present, the drugs resulted in a chemical depression that has stayed with him since. It was as if he was broken and the drugs were taking him piece by piece until there was virtually nothing left. Stuart lost a part of himself that has never returned. I was unable to support Stuart emotionally, I was trying to keep the family ticking along. I would spend long periods of time out of the house as I didn't want to upset Stuart, trying to protect myself from my own increasing feelings of despair. These were the darkest of days and the hardest hurdle we have had to overcome in our 25 year relationship, at times I could've taken the children and left. I feel terrible for my lack of compassion but I didn't like the person that the drugs had created. This episode with the HCV drugs nearly destroyed us and we still bare these dark times and scars many years later, it is the deepest love that is beyond any words and all that we have endured that keeps us together.

30. We were never warned about just how awful the treatment would be. It was the darkest of days for us as I had a three year old and a young baby. Stuart was angry, agitated and would erupt at which point he would walk out of the room and lock himself away. We weren't able to be a family unit, we didn't eat together, I stayed out of the house as much as I could and Stuart couldn't even think about basic questions his brain-fog was that bad. I don't know what my three year old daughter thought of it all. I tried to focus on the children. Stuart was told that things would return to normal after finishing the HCV drugs, but they didn't, we had to create a new normal.

31. Our family life has always been different to that of other families. He has always had a difficult sleep pattern, which is exacerbated by the constant fatigue which is a result of the viruses and the drugs. We have always tried to enjoy an evening meal together as a family. During the HCV treatment, that didn't happen as Stuart couldn't eat a meal. The drugs were awful because Stuart really is the kindest and gentlest man. The drugs created a completely different person. I would take the children out at around lunch time, just as Stuart was getting up and stayed out (at the park or library) until tea time. I still feel guilt at my lack of compassion and not being able to support him emotionally at that time. What has been a loving and enduring 25 year relationship was almost destroyed and we will carry those dark times with us forever.

32. I went back to part time work after my first child, however I was made redundant at the time that I was on maternity leave with our 2nd child. This was now imperative for me to stay at home and look after the children as Stuart is often too unwell to do this. Stuart has tried to work, as we have always needed to earn money. In 2009, he was working 12 hour shifts which started to cause severe exhaustion and his body wasn't able to cope with the rigours of working shifts and having a family. He became very ill and was so fatigued that he told me that he couldn't do it anymore. Stuart was forced to disclose his health issues to his company and they offered him a zero hours contract, so he could at least work around his health and earn some money. He tends to go in for a late/night shift when he can better function (working no more than 16 hours weekly). We have only recently had more financial security, following the recent EIBSS money increase, which has been so wonderful that we don't have to worry constantly about paying the bills. It has been instrumental in taking the pressure of us all as a family.

33. I spoke to Stuart's HIV Consultant in Worcester about the risks surrounding conceiving a third child naturally. Even though I was given every assurance, this was a huge psychological barrier for me to overcome. In order to minimise the risk I had tests at Birmingham Women's Hospital to ensure I was ovulating. Some of the medical profession were very judgmental about our

decision to conceive naturally, despite Stuart telling them that there was research supporting our decision. One senior nurse actually said to me "You are over 40 and need to give this up now", I was shocked. You expect more compassion and empathy from a medical professional. They had not understanding of what we had been through to get to this stage, yet they were using their ignorant assumptions and being judgemental. We have found this from time to time throughout the years.

34. In 2013 I fell pregnant naturally, I couldn't believe it. After going through Assisted Conception I had begun to think i couldn't conceive naturally and had started to believe I was 'sub-fertile'. It was a completely different feeling to becoming pregnant through fertility treatment and I can't really put it into words but it was 'utter elation'. Sadly I miscarried at 7 weeks and it was very difficult for me to get over that. I was devastated and blamed myself. I even questioned myself as to what I was doing and whether this was the right decision to try for another child. Stuart was very supportive and wanted us to keep on moving forward. I fell pregnant again our son was born in 2015.

Section 6. Treatment/care/support

35. It was not mentioned in Stuart's Statement and I wanted to make this point on his behalf. Recombinant was not made available early enough for Stuart, even though there was at least one other co-infected patient of his age receiving Recombinant in the local Health Authority. It was important for Stuart to get access to Recombinant as on blood products there was the risk of repeated exposure to viral infections, which can be dangerous and detrimental to health. This was also the period of time when vCJD was a risk factor in blood products. Stuart had to appeal two or three times to the health authority between 2002 and 2004 when Recombinant was rolled out and each time he was refused, even though there was precedence for him to get it. As such Stuart continued to be unnecessarily exposed to blood borne infections for a further two years.

Section 7. Financial Assistance

36. I refer to Stuart's Statement.

Section 8. Other Issues

37. I have still not been able to speak with my immediate family about this whole matter and everything that we have been through over the last 25 years. I am hoping that giving a statement and the whole Public Inquiry will embolden me to do so. A few years ago I was finally able to disclose to and speak to a close friend about everything. She came with me when Stuart gave oral evidence to the Inquiry. It was a massive weight off my shoulders to finally be able to talk about some of what we have been through. I am so glad that this inquiry is taking place so that people like Stuart, and the haemophilia community, are given a voice. We should no longer feel shame from the judgment of others which has been so unfairly placed upon us. .

Anonymity

38. I do not wish to remain anonymous.

39. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..............Emma Hughes.................................

Dated.................31st July 2020................................