Witness Name: Paula Marie Watt
Statement No: WITN3855001
Exhibits: 0
Dated: November 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAULA MARIE WATT

I, Paula Marie Watt will say as follows:-

Section 1. Introduction

1. My name is Paula Marie Watt. My date of birth is the GRO-C 1965. My current address is GRO-C Manchester, GRO-C. I am married and live with my husband and 24 year old son. I work part-time and live close to my mother and two sisters.

2. I make this witness statement in relation to my late brother, Gary Norman Fitzpatrick who was born on the GRO-C 1969 and passed away on the GRO-C GRO-C 1993, aged 23 from AIDS due to being treated with contaminated blood products.

3. This witness statement has been prepared without the benefit of access to my late brother's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

4. Gary had severe Haemophilia A and he was diagnosed at approximately 5 months of age (GRO-C 1969).

5. I remember Gary was treated with Cryoprecipitate and Factor VIII (FVIII). I am unsure of the full medical name or spelling of the blood products.

6. Gary was treated at Royal Manchester Children's Hospital (RMCH) and he was under the care of Dr Evans. He was later transferred to Manchester Royal Infirmary (MRI) and I remember one of his consultants was Dr Lucas.

7. Gary was treated with blood products all his life, from 1969 until his death in 1993. It is my belief that he was given infected blood products between 1970 and 1985. I do not know the exact time/year in which Gary was infected, but I do remember my mother receiving a letter from the MRI when Gary was approximately 16 years old, which stated that he had tested positive for HIV. This would have been in or about 1985.

8. My mother and Gary were never told or made aware of any dangers or risks of infection by the use of contaminated blood products.

9. As a result of receiving contaminated blood products, Gary was infected with HIV and Hepatitis, although I am unsure if this was Hepatitis C (Hep C) or Hepatitis B (Hep B), as this was never formally disclosed or discussed with my mother or Gary. When it was disclosed that Gary was also infected with Hepatitis it was 'brushed over'.

10. As stated above, I remember very clearly the day my mother received the letter from the MRI informing her that Gary had tested positive for HIV. I remember this because she was concerned, but didn't really understand the implications of what the diagnosis meant. HIV was beginning to be talked about, but it still wasn't commonly understood by the general public. My mother let me read the letter and I know she felt uneasy and scared and she was worried as she did not know what to do. She was invited to a meeting at the hospital with other parents in relation to the letter she received.

11. The letter from the MRI did not provide any information about the infection, it just felt very blasé and brief and typically medical.

12. I don't recall that any information was given to my mother or Gary to understand and or manage the infection.

13. I believe that information about any possible risks should have been disclosed and shared as soon as it was known that there were risks of the blood products being contaminated.

14. My views about the way in which the news was shared with my mother are very strong, and cause me a lot of anger to this day. Because at the time Gary was a minor, he was not told anything and it was left to my mother to deal with when she got the letter through the post. She decided not to tell Gary as he was just 16, and what could she tell him, anyway? We didn't know anything and we weren't guided or mentored. We were 'dumped' with the news and basically left to get on with it. How could something so important be communicated in a letter? It felt so cold and cruel. My mother is particular angry about this because she had asked about any risks some years earlier during an appointment. Her fears were dismissed and not taken seriously (my mother's brother, had read in a medical journal about potential risks of infection and contaminated blood products started to surface in the news). Gary was NEVER told about any risks of infections from blood products.

Section 3. Other Infections

15. I don't know if or what other infections Gary may have received as a result of using contaminated blood products. I remember my mother feeling frustrated because she felt like information was being withheld.

16. As stated above, I confirmed that Gary was also infected with Hepatitis, although I am unsure if it was Hep C or Hep B.

Section 4. Consent

17. I believe that Gary was tested and treated without his knowledge and without his consent (as stated above, my mother received a letter from the MRI stating that Gary tested positive for HIV). I believe that Gary was tested and treated without being given adequate or full information.

18. I also believe that Gary was tested and treated for the purposes of research.

19. I say yes to all of the above because of the way his treatment was often conducted and the way in which questions from my mother were often ignored, dismissed or brushed aside. I remember when my brother was prescribed AZT, and a medical person implied that some patients would be treated with placebo AZT. If there was any time it felt like Gary was part of a medical experiment, it was then. It felt like he was nothing more than a guinea pig in a laboratory. The sad fact is there was probably a lot of medical professionals that were still learning as the real tragedy of suffering unfolded.

Section 5. Impact of the Infection

20. The mental and physical effects were huge on Gary; he suffered with severe anxiety, depression and manic periods. He was emotionally distraught, but did his best to hide his torment from my mother and his family. He became a shadow of the person I grew up with, he became physically frail and vulnerable.

21. Gary suffered from a catalogue of ailments and infections, such as chest infections, pneumonia, shingles, severe skin allergies and conditions including skin lesions, eczema and psoriasis requiring tar treatment. He also suffered from extreme sweating, sickness, vomiting and diarrhoea. He lost a lot of weight, his hair became thin and he suffered with extreme fatigue and nausea.

22. It is extremely painful to remember Gary's demise from a healthy young man, full of hopes and dreams, to a frail, 'old' body of skin and bones. He lost his youth and his energy. My brother died a long, slow and painful death, his

suffering was endured over 4 years from the very beginning of early ailments to his death aged 23. It pains me to recall him so poorly again in my memory. It fills me with an overwhelming sadness and anger, that it hurts. I was with my brother when he took his last breath, I remember my mother screaming, with such agony in her voice. It was a cry from so far within, that only a parent could understand, and a memory that will haunt me forever, because it should never have happened.

23. I don't remember an awful lot about the treatments that Gary received, except he was prescribed lots of tablets and nasal treatments to clear his airways when he had chest infections.

24. Gary did experience obstacles in accessing some treatments – long unnecessary waits in hospital corridors, waiting for transport to and from hospital for appointments; even when he was extremely poorly he had to travel to hospital for injections (when he could no longer inject himself). If he could have had treatments at home that would have made such a huge difference to his comfort and wellbeing.

25. I believe that Gary should have at least been offered treatment injections at home (he came back to live with my mother). I believe his palliative care was very poor; there was no formal end of life plan, no pain relief, it was shocking. His care was left pretty much to my mother.

26. The mental and physical effects of treatments left him exhausted and weary, he was expected to travel back and forth to hospital for treatments that should have been provided to him at home, he deserved to be treated with dignity and to be given some comfort.

27. The impact on Gary's private, family and social life was huge. Gary's relationship with his girlfriend ended as he could no longer care for himself and he was so poorly he went back to live with our mother, as she became his carer. He basically lost his home and independence. He lost his ability to drive and walk. He became withdrawn and isolated from his family and friends, the stigma of his illness was so negative.

28. It was exhausting. My sisters and I were worried about my brother and also about our mother, because she was exhausted looking after Gary at home. Physically and mentally I couldn't concentrate at work, I felt alone and scared, but I didn't know who I could talk to. Mentally I just felt guilt, guilt because I felt helpless and I didn't know how to support my brother emotionally; we never actually had a conversation about HIV and what was happening to him. I do regret that. I didn't really talk about it with friends or socially. The stigma that was associated with HIV was massive, if anything we were encouraged 'not to disclose' Gary's status. That attitude prevented us all from getting support. It was like a big scary and shameful secret, that's how I was made to feel.

29. I found it really hard to deal with Gary's HIV status and I had lots of guilt because I was scared and didn't know how or what to tell people. I was working at a nursery at the time and I remember it being on the news all the time, I felt like it was a 'nasty dirty disease' that should be kept a secret, but this was happening in my family, to my brother, and it wasn't our fault. I wanted to be proud of my brother, instead, everything on the news was negative and clouded by prejudices and sensationalism. The adverts were the biggest fear driver, and I remember them vividly, but he, like many were made to feel shame and were ostracised. We were told and advised on several occasions not to disclose Gary's HIV status by medical professionals, in case it caused media attention. I was once so distraught and overwhelmed by what was happening, that I phoned the Samaritans. I was so desperate to talk to someone who wouldn't judge me or my brother.

30. The biggest impact was on my mother; she became Gary's full time carer. She had, just a few years before, nursed her mother at home before she died and now she was nursing her dying son. She was emotionally and physically exhausted. My sisters and I didn't really talk about it, we just got on with dealing with stuff as it happened, trying to support my mother as best we could. We still avoid talking about it now, because it is just too painful to remember.

31. Gary's education and work was affected; he lost several jobs due to his status – the prejudice wasn't overt, but they found excuses to 'let him go'. His treatments meant his work was interrupted and this was frowned upon, some organisations were not sympathetic at all. Gary always wanted to work, he had aspirations, but his declining health meant he wasn't able to, he found this very difficult, and it affected his self-esteem.

Section 6. Treatment/care/support

32. Gary faced real obstacles in accessing treatment due to his HIV status. He once needed immediate hospital care due to a large wet open wound on his leg and the ambulance refused to take him, until my mother wrapped his leg in plastic bin liners (she had to run to the local shop to buy the bags). It was degrading. They were concerned about how they may become infected, but, it appears the same concern did not apply to my mother. My mother was left to care for her son, provide personal and intimate care needs, but was only offered an HIV test after my brother passed away. My brother was shunned by the medical profession, and was treated like a leper.

33. Counselling support was only offered to Gary towards the end of his life, and only offered to my mother/sister after my brother's death. I feel psychological support was completely inadequate. It should have been available as soon as Gary's HIV status was known, to him and to us as a family. It is beyond belief how he and all of us were largely left to get on with it. The help and support that came, although well meaning was little and arrived too late in my opinion.

34. Since supporting my mother to write her statement, and in writing this, I have recently needed to seek talking to a therapist once again, as this process as opened up some very deep and painful memories. I am indeed surprised that as part of seeking personal impact statements, counselling was not offered at the onset of this Inquiry. I think in seeking information, the emotional wounds and aftermath of every single story of this Inquiry has sadly been grossly underestimated.

Section 7. Financial Assistance

35. I know Gary received a payment (compensation); but I cannot remember when or how much. Gary dealt with this privately. I know he felt ashamed of getting this money. It was not a happy thing, it was money to 'shut him up', that's what he told my mother. The money did not bring him happiness.

36. I believe there was a condition of accepting the compensation that he would not seek further assistance for compensation in the future.

37. I know my mother received some financial assistance for my brother, for example GRO-C. I think it was from one of the Trusts. I know that financial assistance, when it came was very gratefully received and made caring for Gary a little easier for my mother.

38. I have never received any financial assistance from any Trusts or Funds that were set up.

Anonymity, disclosure and redaction

39. I do not wish to remain anonymous.

40. 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...... GRO-C: Paula Marie Watt

Dated 14.11.19