Witness Name: Mrs. J A Waring
Statement No: WITN3241001
Exhibits:0
Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JACQUELINE ANNE WARING

I, Jacqueline Anne Waring will say as follows:-

Section 1. Introduction

1. My name is Jacqueline Anne Waring. I was born GRO-C 1957 and I live at GRO-C Cornwall GRO-C with my husband. I have been his sole carer for 29 years. We have a grown up daughter who has left home and who has recently given birth to a son GRO-C GRO-C

2. I make this statement as the wife of Richard Joseph Waring who was infected with Hepatitis C (HCV) and B as a result of receiving contaminated blood products.

3. **This witness statement has been prepared without the benefit of access to my husband's full medical records.**

4. My husband has provided a Witness Statement to the Inquiry (WITN1721001)

Section 2. How infected

5. My husband suffers from Hemophilia type A classified as severe; with a clotting factor of less than 1%. He was diagnosed when he was about 5 or 6 months old. I refer to paragraphs 5 – 11 of my husbands statement which set out the hospitals and places he was treated and the blood products he received.

6. In or about early 1992 Richard requested his Haematologist carry out a further HIV test as we wanted to start a family, and unbeknown to us at the time a HCV test was also ordered but we were never told the results.

7. It took a little while for me to become pregnant but joyously in 1993 we were delighted to discover I was pregnant. For me this was all I ever wanted; a family of my own. Suddenly just as we were getting used to the idea' I lost the baby and we were both overwhelmed with sadness.

8. In 1993 information was provided by the Haemophilia Society about the possibility of being infected with HCV through blood products and it was recommended that Richard and I should be tested for HCV. We both went to Freedom Fields Hospital (FFH) and were tested, but we never received the results. We made enquires and were led to believe the results had been lost as a result of the move of the Hematology Department form FFH which was closing and moving to Derriford Hospital which happened at about this time.

9. In or about late 1994 we received a letter from Derriford Hospital informing us about HCV and advising us to be tested. We were not really worried much at this time as we had not heard much about HCV so Richard and I had new HCV tests.

10. A little time passed and I had become pregnant again and was expecting our daughter. I popped into the GP Surgery and asked about the HCV tests results and was told mine were in and were negative. I thought "great but

what about Richard's results". I was told they weren't there and to come back another day. By now we had found out a little more about HCV and that it was serious and it could be fatal.

11. I can recall as if it was yesterday when I was told Richard was infected with HCV. The news completely turned my world upside down. I had just popped into our GP's surgery for a check up as I was now 8 months pregnant and I walked up to the desk and asked the receptionist if she had Richards HCV test results yet. The reply was 'Yes, he's positive'. This was in the full hearing of the other patients in the waiting room and with complete disregard to confidentiality and how sensitive this information was.

12. I instantly felt sick and faint. I didn't know what to do with myself in that moment. I felt like I was going to be abandoned I didn't want to lose my partner who cared and loved me. The manner in which I was told was horrendous and a living nightmare. I was ushered into the midwife's room for a check-over; I'm surprised I didn't go into premature labor or lose the baby. I was told to go home and rest and that my doctor would see me later. Richard was working at this time and not due to be home until 5.00pm. I was alone, frightened and left wondering how to tell him.

13. When he arrived home I sat him down on the sofa; I tried to hold back my tears however that didn't work. I explained through the tears what had happened. He was completely stunned, and asked me 'What do we do now?' I didn't know anything more so I couldn't answer. We didn't know of any treatments or what our next steps could be. We were both feeling frightened, shocked and scared. We just sat stunned, weeping together on the sofa, when the phone rang; it was our GP Dr Woods. He told us not to worry and could we come and see him, first thing tomorrow morning. We were referred back to Dr GRO-D (the haematologist) the same week who tried to "smooth things over". A few weeks later we were referred to Dr GRO-D (a Hepatologist.) We went to Derriford Hospital that same week and saw Dr GRO-D and I asked him what I could do to help Richard (i.e. Vitamins, food, etc). He lowered his glasses from his face and lent over his

desk tapping me on the arm and with a very patronising tone; said "there, there Mrs. Waring, have you got your affairs in order"? I kicked Richard's foot under the table and said "come on, we are going". We left, once again feeling lost and cast aside. This started regular 12 week HIV and HCV testing for both of us, a massive strain on us and at the same time we were advised not to be sexually intimate.

14. We received no other advice other than the above at the time we found out Richard was infected. We were left to find out information off our own backs.

15. I believe information on the infection and how to manage it should have been provided earlier and when Richard was first diagnosed back in1992. We were very lucky and by the grace of God that neither I nor our baby were infected.

Section 3. Other Infections

16. I am aware Richard has received letters from the NHS in 2004 and 2009 advising him he is at risk of vCJD which frightened us and caused a significant amount of anxiety and made us question how long we had left together and I became bereft and depressed.

17. After we received the first letter I went to see Dr Copplestone and pressed him to give me the batch numbers which were suspected to be infected with vCJD and eventually he provided them. Richard compared the batch numbers with his records and some of the batch numbers matched. Then in 2009 after the second letter, we were on edge and nervous again, saying it's like the sword of Damocles, you never know when it's going to strike. I went out to my local house group and on my return found Richard unconscious on the floor, hardly breathing. He appeared to have had a seizure, collapsed and sustained a head injury, fractured elbow and bruises. I called an ambulance and warned them of the possible infections, but they didn't seem bothered.

Section 4. Consent

18. I believe my husband was tested without his knowledge, consent or adequate information being provided. In addition to being tested for the purpose of research. I refer to paragraphs 25-26 of my husband's statement.

Section 5. Impact of the Infection

19. When I married Richard in1990 I was happy I had married a caring, gentle and kind man who loved me despite my hang ups about trusting people and being constantly worried that I would be rejected again (caused by being abandoned by my parents when I was only 3 years old and never having a stable home life having never been fostered or adopted.)

20. Richard was frail in his body and spent times unwell but I assumed this was normal for a Haemophiliac. However life as a newly-wed soon took on a sinister side which started with a visit to my doctor for family planning advice. I told my doctor Richard was a Haemophiliac and asked how this would affect any children. She had no hesitation in telling me that if I was going to have girl I should terminate the pregnancy as the girl would be a carrier. I was shocked and replied if Richard's parents had terminated him I wouldn't have this lovely man in my life. Needless to say I never saw her again.

21. The full impact of my husband's infection on him, me and our family is very difficult to convey to its true extent in writing. Regarding the mental effects during his treatment; Richard became very nervous and weak. He suffered from depression accompanied by severe mood swings and a short temper. At times we could hardly talk to him. It was heartbreaking to see this happen to the kind, gentle and thoughtful man I had married.

22. It was like his personality had completely changed while on the treatment. He experienced memory loss and indecisiveness which lead to frustration. The stress I was experiencing alone caused me to lose hair, I felt constantly sad and tired. The infection and effect of the treatment completely killed all sexual intimacy between us as a couple. We wanted more children but because of the risks we decided not to be intimate, not even kissing as Richard often suffered from gum bleeding. Even today our toothbrushes are kept separate and I am super clean around the home especially the bathroom. The reason we are together now is because of the bond we share and the shared faith in Jesus.

23. The physical affects of the treatment where just as noticeable. He looked awful; his hair which had always been long and thick became thin and started to fall out. He had no appetite and struggled to eat which lead to weight loss of nearly a stone and half over the whole treatment. At the review at the end of the treatment ,Dr Camp asked us if we had any questions' I said he isn't as quick as he was mentally and straight away he replied 'it's just a man thing'. This was a completely unacceptable answer, lacking any sense of empathy, from a medical professional. Richard had developed Vitiligo just before he started treatment however it became a lot worse during the treatment, with moles turning red and irritable, then becoming permanently white raw. These were later checked out in dermatology and the staff commented "they had never seen anything quite like this before" and they would monitor this in case of any progression or changes. He would suffer from intermittent rashes across his body.

24. The side effects of the treatment Richard was receiving had a significant affect on our daughter who was about 6 at the time. There was one incident I remember very clearly. We were sat at the table with knife and fork in hand. Richard wasn't able to eat and I was trying to encourage her to eat and she was in tears and saying "I don't want to live in this house anymore." This is a heartbreaking thing to hear your own child say. Those were very

dark days for our family. I had to prepare for the worst, so enrolled in a NVQ level 3 in childcare, so I could support myself and Charlotte if he died.

25. Although I worked extremely hard to obtain my NVQ (some times surviving on 2/3hours sleep a night) and was offered a temporary position at a local school, I had to turn the job down, after speaking to the benefits office as they couldn't assure me I would be able to regain my benefits when the work finished and I was concerned about the uncertainty of Richard's condition and that we didn't lose the benefits we depended on to live.

26. The impact it has had on me personally has been severe. I feel like I don't truly know who I am anymore; that I've lost my identity. In nearly 30 years I have had only 3 days break. We tried to apply to the Caxton Fund for funding for me to go away for a few days during Richards's treatment. However, as we couldn't provide an accurate estimate without booking (which we couldn't afford) they denied the request.

27. I have experienced crushing fatigue, with the constant feeling of bereavement without losing the person, and the stress of the inability to plan for the future. As explained above our sexual intimacy as a couple was destroyed by this infection and treatment. This had a knock on effect as I wanted at least 2 children however we were only ever able to have one. I still struggle today; I cannot sit still even when trying to relax. I don't know how to relax anymore.

28. The stigma experienced against our family has been great due to my husband's infected status. One example of this are, when my daughter and I pulled up in a petrol station after some media exposure on "Young Carers" I went into the petrol station store and went to the counter, I was about to pay and I looked down to see our daughters face plastered on the front of the newspaper. The server looked down and said 'it's you isn't it' I didn't react and finished paying; and got back in the car. When I looked out I could see him pointing at us and ushering his colleges over to have a look. Another example occurred after the funeral of a fellow haemophiliac friend

where our daughter Charlotte (a minor at the time) was photographed without our knowledge and a photo of her at the graveside was in the local newspaper the Plymouth Evening Herald.

29. Around the time the news came out that HIV contaminated blood was given to hemophiliacs; the headmaster of my daughter's school a David Bradford (Elburton Primary School) phoned our home at 8.30 am to speak to me. He told me the press had been contacting the school and that some of the parents were worried about potential infection from my daughter. I told him the truth; my daughter did not have any infection and that there is no risk to any other students.

30. On another occasion after the press and BBC were highlighting HCV Charlotte was taunted by year 6 boys saying her dad was a "spaz and had AIDS "My heart broke this was obviously gossip between parents and kids overhearing. I spoke to David Bradford and he said he would have a word with parents. I never heard back from him

31. This highlights the general lack of knowledge and understanding of the general population; and that their worries were fueled by the scaremongering media.

32. We have been restricted in friendship. I can recollect at a coffee morning I overheard a group of women saying not to come to our house for coffee as you will catch "It" from the cups. I would often stand alone in the playground with all the other parents avoiding me.

33. As Richard's income had declined by over half we had no money to go out for a meal/treat for Charlotte, had no holidays for 10 years(bar a week at my friends cottage when Richard was receiving treatment for his HCV.

34. I had to shop in charity shops for clothes or rely on the goodness of others. When Charlotte started senior school we couldn't afford the uniform so a teacher and the dinner ladies clubbed together for an Asda Voucher so I could buy a uniform.

35. Seeing Charlotte, lonely and frightened growing up with no money and maybe no daddy seeing Richard but not having a proper relation with him due to the side effects of the treatment was heart breaking. At 12 she was so wasted away she only weighted 5 stone couldn't eat, always felt sick, and was anxious permanently. Charlotte was investigated at Bristol Children's Hospital but they found nothing apart from slight regurgitation so I think the symptoms were a direct result of the home situation. Charlotte would ask anxiously every afternoon when being picked up "Is Dad in the car is he ok"?

36. I refer to paragraphs 40-44 of my husband's statement which set out the financial repercussions of the HCV infection and treatment.

Section 6. Treatment/care/support

37. We experienced difficulties and obstacles in obtaining and maintaining treatment. Richard was 3 months into his treatment and we went to the hospital to collect a regular repeat prescription for Ribavirin and Interferon; only to be told by the receptionist that we would have to pay as they were trying to balance the books and claw back some pharmacy finances. I was livid, and marched over to speak to the hospital administration. I demanded to see one of the administrators.

38. I was fobbed off at first and told to go have a tea while they investigated. On my return, I was told by a man in a suit that the position hadn't changed and we had to pay. This was the final straw. I told him I would be stopping at the local BBC newsroom on the way home as it was outrageous that they were asking, us to pay for a treatment for an infection caused by them. Once I said that, they found a 'solution' and the costs were waived. This was after the Government had increased the funding for treatments!

39. Counselling was offered when we first found out about the infection however that never bore any fruit. No psychological help was offered on a

long term basis. Instead we had to go off and be proactive in finding somewhere which could help. We found a charity which ran the Eddystone clinic in Plymouth they were very nice however they didn't quite understand our situation as they were mainly dealing with drug users, sex workers and homosexuals.

Section 7. Financial Assistance

40. I refer to paragraphs 51 to 58 of my husband's statement which set out the financial assistance received and issues encountered with the Trusts/Funds/EIBSS.

Section 8. Other Issues

41. We have lost a lot of friends, as have all in the haemophilia community. It has left us feeling isolated as many people have no idea of what we have had to deal with. We want people to be held accountable for their actions and for the truth to come out. We shouldn't have to go 'cap in hand' to the Trusts/Funds to get money, it should be awarded to the families and individuals who are still alive after this tragedy. Today we have a huge sense of relief that our voices are at last being heard, and no longer screaming help, inside. This obviously does not change or alter the past; or take the pain away, but as a family we stand together (with the joy of our new grandson). I hope we face the future with hope and financial help so that the next generation does not have to deal/live like this. We stand for our new grandson to help prevent and expose this for him and for his generation not to be used like cattle and experimented on.

Anonymity, disclosure and redaction

42. I do not wish to apply for anonymity and I am prepared to give oral evidence to the Inquiry if required

Statement of Truth

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

Signed.. GRO-C ....

Dated......2nd July 2019.......