

ANONYMOUS

Witness Name:

Statement No: WITN1388001

Exhibits: WITN1388002

Dated: February 2019

**INFECTED BLOOD INQUIRY**

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FIRST WRITTEN STATEMENT OF

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I,  will say as follows:-

**Section 1. Introduction**

1. My name is  DOB  1966 and I live at
2. My ex-husband  was infected with HIV and Hepatitis through contaminated blood products. I was infected with HIV as a result of 's infection.
3.
4.  has given a statement to the Inquiry (WITN1387001).
5. 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 set out in the medical chronology at the end of this statement.

**Section 2. How infected**

6. I met [ H ] when I was 15. He lived a very normal life and you wouldn't have known he was a severe haemophiliac. He lived life to the extreme and then an extra 10%, much to the annoyance of his parents.
7. [ H ] and I were very like-minded and wanted to get on with living our lives. We brought our first property in 1983 and subsequently moved in together when I was 18 years old and we got married shortly after on [ GRO-B ] 1984.
8. [ H ] had been administering Factor VIII for some years by this stage. He had previously suffered from one adverse reaction to his treatment, which we later found out to be a result of an infection with Hepatitis A and Hepatitis B.
9. While we were living with his parents [ H ] was very ill with Glandular Fever. The doctor said that this would have been triggered by something, and suggested that we go to the Haemophilia Centre as there were some things that were above his knowledge. Following his diagnosis (and when we understood more about HIV) we suspected that this was when [ H ] seroconverted.
10. At this time I was working a couple of jobs and [ H ] was very career driven. For me, my jobs were just a means to an end and it was all about building a life together and a family. I really had no career aspirations and was just family driven.
11. In February 1985, [ H ] collapsed at work. [ H ]'s father rushed us both to hospital, where a doctor said that [ H ]'s HIV must be developing into full blown AIDS.
12. [ H ] had not been diagnosed with HIV at that point and, as I understand it, there is no evidence in his medical records that he had even been tested by then. I therefore, like [ H ] believe that his records are incomplete.

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13. In late 1985, [ H ] and I were called to the hospital where we were told that [ H ] was HIV positive. We were told very little about the virus, its prognosis and routes of transmission. We were told not to tell anybody about the infection and we left the hospital in a daze. They arranged for me to be tested also, and fortunately the test came back negative.

14. In August 1985 I was pregnant. [ H ] and I felt that we were too young to be parents and we were being bombarded with information about the risk of HIV. It was a terrible time and we were at a loss about what to do. In the end I decided to have a termination. There is now shown to me marked **WITN1388002** a copy of the letter sent to my GP which effectively confirms the terrifying position that we were in; we didn't know if [ H ] was going to test positive but were being told that the risk of our baby having HIV if he was positive was sufficient to justify an abortion.

15. Shortly after this, there was a clear change in the workings of the haemophilia centre. Appointments were arranged so that you wouldn't see any other patients and you would be kept in a private waiting room on your own, whereas before there would be 30 haemophiliacs together in a waiting room. We were made to feel like it was just us going through this.

16. When [ H ] and I separated in 1997, I left our home and went to stay with my mum. Within six months I was very ill. I spent the next few months going to and from the doctors, and my weight had dropped to just five and a half stone. The doctor said that he believed I either had cancer or HIV, and asked if I knew anyone with HIV.

17. I was tested in June 1999 and was told in July that I had tested HIV positive. They believed that I had probably been infected around 1989.

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19. After my tests in 1985 and 1989 I had repeatedly been told that I didn't need to be retested. We were even advised by the MacFarlane Trust that I shouldn't keep going for tests as if I tested positive I wouldn't be able to get a mortgage or insurance. I felt I needed to stay strong.

### Section 3. Other Infections

20. I know [H] was told that he had may have been exposed to vCJD, but I am not aware of any other infections I may have been exposed to.

### Section 4. Consent

21. I consented to be tested for HIV in 1985, 1989 and 1999.

### Section 5. Impact of the Infection

22. [H]'s HIV diagnosis destroyed our lives and our marriage and a chance for everything I had hoped for; children, softness and love. We were young with our whole lives ahead of us and our future was taken away because the powers that be thought that, as a haemophiliac, his future wasn't worth anything.

23. Every time [H] had a cold or some unusual illness I thought he was going to die. It was unbearable and devastating on a daily basis. There was no escape and no support to help up comprehend and deal with the terrible fear that his diagnosis brought.

24. In 1989 I found out that I was pregnant. I discovered this fairly late-term and [H] and I hadn't even told our parents. I went to see my GP, who refused to see [H] and he told me that as my husband was HIV positive, there was a chance that both myself and our baby may have been infected. My GP wrote to Dr Hill explaining the situation; however I have never seen that letter or Dr Hill's reply.

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25. It says in my medical notes that I 'asked' to have a termination. This is a very bold choice of words. I was a frightened young woman who went to my GP for help, and I was made to feel like I had no other option than to terminate my pregnancy. I can no longer even comprehend what was said to me to make me agree with what they wanted.
26. When I was seven months pregnant, I was put in a room with biohazard stickers everywhere. I wasn't allowed to leave the room, not even to go to the toilet – I was given a commode instead. I don't remember much about that day at all; I had been given so many drugs that I was pretty much out of it. There were plastic sheets all over the room and the nurses came in wearing space suits. I was made to feel like I was a murderer by them, and that is how I continue to feel to this day. I was even told by one of the doctors that people like me should be sterilised. I was told afterwards that my baby was a boy.
27. The next day  and I went home and never discussed it again. I have no idea how I made it through that weekend, and then on Monday I had to go back to work as if nothing had happened. A few days later my breasts started leaking when I was out with friends. It was a horrific time for me.
28. I was offered no counselling or support throughout this time. I have since seen many counsellors and try to meditate to forgive myself. I have nowhere to go to mourn for my baby.
29. The fact that I had two terminations as a result of the Contaminated Blood Scandal is something that I struggle to live with on a daily basis. I don't know how I made the decision once, let alone twice. I have been unable to forgive myself and this has had a massive impact on me over the years; one that I can't even put into words.
30. Our marriage had gradually been deteriorating since s diagnosis. We lived two separate lives. I was working four different jobs; I would go to work in the morning, come home to care for  before going out to my next job in the evening. The only time I would not be working was a Monday morning,

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and even then I had to go out and do the food shopping for us. It was all completely exhausting.

31. We had no one but each other. There was no one to sound board off. We were isolated from all other infected haemophiliacs and wives. Even if we were given the opportunity to meet another haemophiliac couple it would have really helped, but we were denied this opportunity.

32. Seeing each other was a constant reminder of [H]'s infection, and as such we drifted apart and began to live separate lives outside of the marriage. The turning point for us was after the 1991 litigation, at which point it became clear just how serious [H]'s infection was and that he wasn't going to be here much longer.

33. We were in a mess financially. [H] has received the lump sum in 1991 and by 1993 we were in court as we had a loan that we were unable to repay. Fortunately, Ann Hithersay from the MacFarlane Trust intervened, and we were just about able to keep the house.

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It was so difficult to eventually end the marriage; I was so broken hearted. If [H] had never confronted me about everything then I'm not sure it would have ever come to a head.

35. I don't feel like I am a good person or that I have led a good life, and it pains me that I was robbed of the opportunity to have children and grandchildren.

36. It is still so hard trying to live a normal life with everything going on. I struggle to concentrate at work and I am constantly worrying about the Inquiry. I do yoga and I meditate as a distraction tactic. I try to hold on to some shred of normality, but it is all a lie. My past is not something I can discuss and memories and decisions stay locked away.

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37. Every bit of literature you read about closure talks about opening your mind to who you are, understanding it, dealing with it the best you can and walking away. But it is impossible to do that here as I have to live with my infection every day, and I can't even take solace in the fact that justice has been served. Had we got anything from the Archer Inquiry we could have just walked away and tried to move on. But as that came to nothing, we are having to live through it all again. It just doesn't end. Mentally it is absolutely exhausting.

38. From a physical point of view I am mostly fine. I still suffer from opportunistic infections, but generally my medication is fine, I do a lot of running and I eat well. I do however suffer from cognitive issues such as concentration and memory. The doctors often try to put this down to my anxiety, which is absolute rubbish.

39. I am self employed but I am struggling at the moment. I am making too many mistakes as a result of my concentration issues, which isn't good for my confidence and mental health. I hope to stop soon and do some volunteering instead, where I can still feel like I am doing something good without the pressure or expectation.

40. **P** is so down to earth and nonchalant. He just looks after me. It appears to me that he hasn't suffered from much of an impact, although it must be tough for him to deal with my mental health.

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### **Section 6. Treatment/care/support**

42. There was a support system available to me as someone newly diagnosed. I think I was given a lot more support than **H** had been offered after his diagnosis and than what we were offered as a frightened young couple.

43. I found one support group I was advised to see, The Worcester Foundation, I found it to be a predatory environment. They thought I was probably someone that could be taken advantage of sexually or a drug addict because there was no other logical reason why someone like me should have HIV.

### **Section 7. Financial Assistance**

44. [ H ] and I were a part of the 1991 Litigation, at which stage we were unaware of my infection. We were told that if we didn't sign a waiver then nobody would receive anything, so we had no other option than to sign it.

45. I became a MacFarlane Trust primary registrant in 1999. I received the MFTP2 payment of £23,500 as an 'infected intimate'.

46. [ H ] and I received a £1000 'bereavement payment' after the loss of our child.

47. The only grant I ever received from the MacFarlane Trust was a moving grant after [ H ] and I had broken up. I have never asked for more because I have been working. In any event, these support schemes tend to work in a manner of whoever shouts loudest gets the most support.

48. The left over funds from the MacFarlane Trust have been given to the Terrence Higgins Trust with absolutely no consultation with the people that are entitled to receive that money. I have tried to communicate with them to understand the massive shortfall in the money they were given by MacFarlane, to no avail. They have been given £600,000 of MacFarlane Trust money and they are still refusing to support us.

49. EIBSS appear to think that HIV is no big deal. We don't get any support from a health perspective and they are oblivious to the health problems caused by the infection and the effect on our mental health.



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50. People who were infected with Hepatitis C are offered much more support. They are automatically entitled to a pre-payment funeral plan if they have Stage Two Hepatitis, and woman infected with HIV are considered 'infected intimates' whereas women with Hepatitis C are considered infected in their own right. As there are so few people with HIV left, they probably get one call a week from someone with HIV and are bombarded with calls from people with Hepatitis C, so they just don't understand what we are going through.
51. I went through the lengthy application process to apply for a boiler, but this application was refused. It wasn't until I went to an EIBSS meeting and requested this in person that they were willing to change their minds. It shouldn't be this difficult for people to receive support. You are never made to feel like a person, I am just a number to them.
52. No campaign group or organisation has ever spoken for Positive Women via HIV through Factor VIII that is why we have our own campaign group. It is not even known about and there are no figures relating to how many women have died through infection via this route.
53. No HIV organisation has ever supported or even understood the mental anguish and torture that those haemophiliacs and we, as their infected partners, have had to deal with for over 30 years.
54. As MFT registrants (and in comparison to the treatment of those infected via whole blood who are known as the Eileen Trust registrants) we have been undermined and unsupported as HIV infected Haemophiliacs and infected intimates. This really needs to be investigated further.
55. As so called "infected intimates" we have not had the same lump sum payments as Haemophiliacs who were MFT registrants and also those who were Eileen Trust registrants. There is a massive discrepancy that we have continually asked the DHSC, MFT, Haemophilia Society, EIBSS and now The Terrence Higgins Trust to support. Over the last 15 years I have campaigned

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for this inequality and discrimination to be rectified and for us to be recognised as registrants in our own right, in the same way as Hepatitis victims.

### **Section 8. Other Issues**

56. This is not about looking at our physical health now and considering the position we are in with medical intervention, it is about considering where we would have been had this never happened. The decisions we had to make and the life we had to lead knowing we were affected by a virus killing millions of people worldwide.

57. To move forward there has to be closure. Once this witness statement is finished that is me done. I cannot have any more involvement. It is too heartbreaking, and it leaves me feeling a lesser person every time I explore and look back. It is seriously unjust that we must constantly relive this nightmare.

### **Anonymity**

58. I would like to apply for anonymity.

59. I do not want to give oral evidence to the Inquiry. My mental health would not be able to deal with speaking about this in a public domain.

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**Statement of Truth**

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

Signed.. GRO-B .....

Dated 28/2/2019.