

Witness Name: Fiona Rennie

Statement No:WITN2933001

Exhibits:0

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF FIONA RENNIE

I, Fiona Rennie will say as follows:-

Section 1. Introduction

1. My name is Fiona Rennie of GRO-C
GRO-C I was born on GRO-C 1965.
2. I currently live with my husband and three children. I work as a paramedic and I also run a play centre alongside my friend.
3. This witness statement has been prepared with benefit of access to some of my medical records.

Section 2. How infected

4. When I was four years old, GRO-C I were diagnosed with Von Willebrand's Disease at Margate Hospital. I was under the care of Dr Sterndale. Every six months we would go for various tests and had clotting factors done.

5. I lived my young life as a sufferer and I was told that I could not undergo any type of surgery unless it was an emergency. The hospital had given my mother indications of what I could and could not do, so a lot of childhood was restricted. By way of example, it was advised that I should not engage in any school sporting events, which I would have enjoyed had I been allowed to participate.
6. As a teenager, I was very conscious about my teeth, but no dentist was willing to remove any of my teeth as they feared this may lead to a haemorrhage. I was often bullied at school because of my teeth and it always adversely impacted on me. My friends were awkward around me and I was extremely embarrassed by it. In fact, on one occasion, when I was eight years old, I removed a tooth myself using a tin of talcum powder and my father's pliers. Nevertheless the situation did not improve and overall my teeth were still terrible. When I turned thirteen, I went to see my dentist crying and said I could not continue to look like this. I was adamant that I wanted to remove my front teeth to help with my appearance.
7. In October 1981, when I was sixteen years old, my dentist finally managed to refer me for a surgical procedure to straighten my teeth. Because of my bleeding disorder I was informed that the procedure would need to be supported by Factor VIII. I did not know what this was at the time, but I was desperate to have my teeth done. I was told that everything would be fine and at no point was I made aware that the blood product may put me at risk of infection. If my mother had been told of any such risk, she would have withdrawn consent from the operation immediately. The actual procedure was a couple of hours long, but in total I was admitted in to hospital for eight days and I received Factor VIII both prior to and after the operation.
8. In 1985 I was pregnant with my eldest daughter. When I was thirty eight weeks pregnant, I was warned that because I had Von Willebrand's Disease, I would need to receive cryoprecipitate when I gave birth. It was explained that the Cryoprecipitate was an artificial form of blood. In addition to this I was told that I would need to have my child in isolation as there was a risk that my

child would be born HIV positive. This is because on the Haemophilia database records my doctor noticed that I had received Factor VIII when I was 16.

9. I received a phone call advising that I needed to come to the hospital for a blood test. Luckily, my mother was the senior midwife on the unit and so she came to my house to take a blood sample. Due to the short expiration date of Cryoprecipitate, I was informed that I was to undergo a forced labour within two weeks. The Cryoprecipitate was only there in case of an emergency, but it was never administered as I never bled during labour. Thankfully my baby was born healthy. GRO-C

10. I wanted to have another child, so I had gone through IVF, and after trying a few times, I eventually became pregnant with triplets. This was before I was diagnosed with Hepatitis C and by then, I knew that I did not have HIV. My doctor also ran a screen test and could not find any trace of Von Willebrand's Disease. I found this to be odd as I was sure I suffered from the Von Willebrand's Disease.

11. My role as a paramedic required me to undergo regular screening. We were vaccinated for Hepatitis B and I was screened to test my antibodies. In June 2011, without my knowledge or permission, during the screening, I had been tested for Hepatitis C Virus (HCV). In January 2012, I was told to give occupational health a call and when I did they informed me that I had tested positive for the HCV. Occupational health told me that they would need to conduct further blood tests and that I would no longer be able to work as a paramedic whilst these tests are going on. I consequently lost my job as the blood tests confirmed that I had been infected with the HCV.

12. I got no help from anyone at Margate Hospital so I immediately went to my GP, Dr Jain. I had to inform her that I had tested positive for Hepatitis C after which I was made to go through the tests for Hepatitis C again. Once the results came back positive, she referred me to a specialist at Margate called Dr Ballinger. I had to wait eight to twelve weeks before I got to see her. My husband accompanied me to that appointment. Dr Ballinger told me that she

would test my genotype. If I was type one or four, she would only be able to offer me palliative care which would help me with my symptoms but it would not clear the virus. If I was type two or three, she would refer me to another doctor and I would have an 83% chance of clearing the virus. My results were delivered to me through the post. In the letter it stated I was genotype one and that they could offer me a biopsy so that I could find out how long I could live for.

13. Before they could do the biopsy, they needed to reassess the Von Willebrand's Disease as there was a risk I would bleed. Following that assessment I was invited to the hospital. I attended that appointment alone and went into the consulting room where I was faced with a team of medical professionals, namely the HR officer, some consultants and two nurses. I felt overwhelmed and had I known what I was walking into, I would have taken someone with me. They told me it was all good news and that I could go ahead with the biopsy. They told me that I must have had a low substance level to begin with and that I had grown out of the Von Willebrand's disease. I referred them to some previous correspondence which confirmed a level of twenty five, which was very high, contrary to what they were saying.

14. Following this I went through with the biopsy and it was revealed that I had liver disease, though I was not told which stage I was at. I was told that my liver would deteriorate on average one stage every five years. Dr Ballinger was so sure that there was nothing she could do to help me that she cancelled all my future appointments.

15. One night my husband [REDACTED] **GRO-C** met a [REDACTED] **GRO-C** who explained that he was Hepatitis C positive and genotype one. That [REDACTED] **GRO-C** went on to describe that he had received treatment for Hepatitis at Paddington Hospital. My husband received all the details from this man and we submitted this to our GP. I was referred to Professor Taylor-Robinson and underwent combination therapy to clear the HCV. During treatment at Paddington Hospital, I was under the care of Dr Darr and my nurse was called Nicola Cook.

16. On finding out that I had been infected with the HCV, no information was provided to me about the infection and I was not given adequate information to help me understand and manage the infection. I feel that not informing me that I was being tested was wholly inappropriate, particularly considering that the result could impact my entire livelihood. In addition to this, the manner in which I was treated whilst pregnant and being told that my child may have HIV, when I never knew that I had previously been at risk was extremely hostile.

Section 3. Other Infections

17. I worry constantly that I may have Creutzfeldt-Jakob disease (CJD) and other as yet unknown infections other than the HCV as a result of being given the contaminated blood products.

Section 4. Consent

18. As I have mentioned above, I do believe that I have been tested without my knowledge, without my consent, and without being given adequate or full information.

Section 5. Impact of the Infection

19. After I received my diagnosis I was neither here nor there. I became overwhelmingly paranoid that in my line of work, I may have infected all the patients I had ever cared for. I thought about the most serious of cases, but in actuality I had probably never infected anyone. I never had cuts of my own during work and I always use Personal Protective Equipment (PPE) when necessary whilst at work. After finding out, it took me an entire year to tell somebody. I now realise that this was a mistake as my friends and family were extremely supportive. At the time I felt it was better if no one knew.

20. For over twenty years I had issues with my knee and I also developed thyrotoxicosis. This can be linked to the HCV as well. Dr Withrington told me

that my x-rays and scans showed that there was nothing wrong with my knees, but that there was a viral infection present.

21. At Paddington hospital I participated in a drugs trial. I received Interferon, weekly injections, Ribavirin and Telaprevir. The entire treatment lasted six months. I was told prior to treatment that there may be considerable side effects, but I was looked after. It took Dr Darr almost four hours to chase up my medical records. He needed this before I could go on the trial. He told me that there was a 90% chance I would clear the HCV. I faced further difficulties in beginning treatment as Dr Darr needed to obtain funding from Margate Hospital first. The nurse assured me that she would get this funding and she was very good, but I was running out of time. I was told that if I did not practice as a paramedic in the next eighteen months, I would lose my licence to practice. Dr Darr knew of the urgency and reassured me that the treatment would be completed on time.
22. I do feel as though this treatment ought to have been offered earlier. I should have found out I had been infected with the HCV earlier too. When I was pregnant with my first child and they thought I had HIV, they should have tested me for Hepatitis, but I am unsure if they did. I believe, occupational health must have known I was at risk of the HCV as they tested me for it, albeit without my knowledge or consent. I was also on the Haemophilia database register and so they must have known that at some point I would have been exposed to Factor VIII treatment.
23. Dr Ballinger's approach towards my care was appalling. As soon as she discovered I was genotype 1 she offered me a biopsy however on receiving the results she practically gave up on me. Dr Ballinger told me that she had cancelled my upcoming appointments as there was no treatment available for me. I thought that was it and I was going to die. I never spoke to her again. She destroyed us as a family and made me feel very mentally unwell. I never reported her as instead I fought my own battle to become well again. I was not strong enough to take on Dr Ballinger at the time.

24. Physically, the side effects of the treatment were draining. The hardest part was trying to swallow fat to line my digestive system before taking Telaprevir. I would be heaving constantly and my family would try to distract me whilst I tried to down the fat. I would often panic, but I knew that if my stomach was not lined, the tablet would cause me considerable pain. Other side effects included vomiting, skin irritation and severe paranoia. The further I progressed the worse my paranoia got. Even after the treatment was complete, it took me almost six months for my situation to improve. Overall I was very depressed. It was challenging but I focused solely on the fact that I wanted to get better. On top of this, I had to travel into central London to get the treatment I needed to fight my HCV. This was an expensive, lengthy and exhausting journey through the underground. I recall on one occasion I was returning home after treatment and my friend had to physically hold me up in the tube.

25. My husband and children suffered along side me. They were all worried and would be extra cautious particularly around my toothbrush and razors. I recall that my daughter had cut her hand whilst opening a can of beans one day and I could not go near her. I stood at a distance and I just screamed at her thinking that if I touched her, she could be at risk. My eldest knew that I had Hepatitis C as she was old enough. She had her own child when I told her.

GRO-C

GRO-C This was an extremely difficult time for both me and her. I would always blame myself if she was also infected.

26. I later had triplets who were only eleven when I started treatment for the HCV they also had to be tested for HCV. One of my daughter has a heart condition and thought that she may not be able to receive any treatment for it. I feared that the stigma was far too great and felt they were too young to know, but after starting treatment I had to tell them. I insisted that it was a family secret, and if they told other people then their friends would not like them anymore. I thought if their friends found out then there was a possibility that their parents would assume that I am a drug addict and their children would be banned from coming round to my house. Their birthday parties and other social gatherings would never be the same. My triplets are now eighteen and their

friends are old enough to understand that they cannot walk into my house and 'catch' the HCV.

27. My husband was very supportive of me **GRO-C**
GRO-C
GRO-C If I had died, my husband would need to care for our children.

28. My way of coping with the HCV and the side effects of the treatment was to stay indoors hiding. I had three very good friends and one in particular kept coming around my house. She realised that something was wrong so I eventually told her. I lost touch with other friends and besides that there was the mother's network at school. The conversations I would have with them were geared around our children more than us, but I would hardly socialise with them as I did not want to lie to them. Before my diagnosis, I also ran a dance class which I stopped immediately after finding out about my infection. I did not want to be judged by people and I felt like everywhere I went, people could see through me and that I was infected with the HCV.

29. In terms of my education, since realising that I was misdiagnosed with Von Willebrand's disease, I look back and think that there was so much I could have done. I could have participated in those sporting activities, and I could have gone through with my teeth straightening operation without fearing that I would bleed to death. I would never have needed Factor VIII to support me.

30. Needless to say, my work was probably most affected. I had worked as a paramedic for over twenty years and because I was Hepatitis C positive, I had to give up my job. Soon after I learned about my diagnosis, I went to an ambulance station where I saw an occupational health nurse. As I was leaving the room, she asked me if I had been promiscuous when I was younger. The stigma was there even with medical professionals. I was allowed back to work as a paramedic, however, I experienced considerable difficulties in getting there. I went for an occupation health screening and Dr Darr had to write me four letters. In one of them he wrote in block capitals, 'SHE POSES NO

THREAT TO THE PATIENTS'. Overall it took me two years to return to work fully after clearing my virus.

31. I now own a play centre business with my friend. We struggled to get Ofsted approval to register our business as my HCV was a major impediment. My GP wrote me a letter stating that my infection had been cleared and that it was safe for me to run a play centre.

32. I am now clear of the HCV, but I still feel haunted by it. I have also been left with a stomach ulcer and inflammation of the oesophagus that remains on going since my treatment for the HCV. Recently, I was experiencing some pain and went to see my GP. They jumped to the conclusion that I had relapsed and asked me to be retested. I knew the implications of going for that test as I had already lived through it. I refused to be tested as I feared I would lose my job a second time. The GP reassured me and said that would not happen, but I did not believe her. I did not want the Hepatitis C status to be the cause of more grief.

33. My husband and I had always lived on two salaries, so for me to be out of work for so long had a massive financial strain on us. We lost our house due to financial hardship and had to move to a smaller house. I only received limited benefits. On top of that it was costing us hundreds of pounds a month to travel to Paddington Hospital for my treatment. We also had triplets to care for and it was hard for my husband as whilst I was unwell, he was working full-time. At the same time he would have to do the school runs, feed the children, and otherwise take care of them.

Section 6. Treatment/care/support

34. I did face obstacles in obtaining treatment for my HCV. Margate Hospital was wholly unhelpful in that. I felt as though I was always waiting. Once I joined the trials at Paddington Hospital, I felt much better. The head nurse told me that I should stop worrying and was very helpful with any questions I had.

35. I regularly went to my GP after I was diagnosed with the HCV. My GP thought I had been showing suicidal tendencies so I was offered Cognitive Behavioural Therapy sessions for twelve weeks after which I had to ask for more sessions. This was with the KCA counselling group who is now known as Think Action. I wish this had been offered to me sooner as speaking to a stranger definitely helped me. To this date, I use my counsellor's strategies and coping mechanisms.

Section 7. Financial Assistance

36. In 2013, I received a Stage I payment of £20,000 from the Skipton Fund, six months after I was diagnosed with the HCV. I invested this money in to the play centre business. I also receive £4,600 a year and I get the winter fuel allowance. I have not signed any waiver, nor was I asked too.

Section 8. Other Issues

37. I would emphasise the difficulty I faced in getting my business registered. I had a suitability meeting with advisers from Ofsted as I was concerned that I would not get approval, even though my doctor had made it very clear that the HCV was in the past.

38. There are two aspects to the contaminated blood inquiry that I feel very strongly about. The first aspect is about accessing healthcare without prejudice and without feeling like I am begging for help. Given what I have been through, and the fact that the risk of cancer in me is high, I feel like I should be entitled to a scan every year. I should not feel as though I have to beg to receive this. I recently went for a liver test but it took a lot of persuading to get there. The second aspect relates to the blood being contaminated and the fact that there was a massive cover up. When I look back at my Haemophilia records, I cannot understand why nobody wrote to me earlier. They could have protected the public as I had been working as a paramedic taking all kinds of risks.

Anonymity

39. I do not want to be anonymous.

40. I would like to provide oral evidence at the Public Inquiry.

Statement of Truth

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

Signed..... 

Dated.....28th February 2019