Witness Name: VALERIE BRENDA SMITH
Statement No: WITN3956001
Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF VALERIE BRENDA SMITH

I, VALERIE BRENDA SMITH, will say as follows:-

Section 1. Introduction

1. My name is Valerie Brenda Smith. I was born on GRO-C 1960 and I live at GRO-C.

2. I was infected with the Hepatitis C Virus (HCV) from a transfusion with contaminated blood and have developed cirrhosis of the liver as a result.

3. This witness statement has been prepared without the benefit of access to my medical records.

Section 2. How Infected

4. I was given a blood transfusion on GRO-C 1990 at the British Forces Rinteln Hospital, Germany. The blood I was transfused with was supplied by the British Red Cross in Germany. I was first tested positive for HCV in March or April 1995. In or around 1996 or 1997 The Ministry of Defence confirmed that I had contracted HCV through the contaminated blood transfusion I received

on GRO-C 1990. From 1995 when I was told that I had HCV up until 2015 when I finally cleared the virus. I have had several biopsies and failed clearing attempts.

Section 3. Other Infections

5. I am not infected with any other virus than HCV.

Section 4. Consent

6. I was given the transfusion after the traumatic birth of my son Stuart and several blunders at the hospital, resulting in his death ('stillborn' on his death certificate). I was not warned of the risk of being exposed to infection from the transfusion. Little did I know then that the events on the day of GRO-C 1990 would change my life forever.

Section 5. Impact of the Infection

7. The convalescent period following Stuart's birth and death was slow and long and I gradually noticed things were not right. I did not know what was wrong. I just didn't feel right but didn't know why. My body never felt the same and I just felt mutilated.

8. In June 1990 we arrived on the beautiful island of Cyprus as my husband had been posted there from Germany. It was just what we needed after the previous months.

9. In Cyprus, I still wasn't feeling great but I put it down to the heat on the island. As the days and weeks passed, I tried to ignore how unwell I felt. I didn't know if it was 'just me' given what we had had to endure in the previous months but my energy levels were not as they had been before. When things didn't improve I went to see the GP and I continued to do so right up until February 1993 when we left the island. During this time my doctor tried without success to get to the bottom of what was wrong. I recall him once

saying that I had all the symptoms of hepatitis but no fever. When my bloods were taken the liver function test results were abnormal and I was booked in to have a biopsy at Akrotiri Hospital a couple of weeks before we were to leave the island. Upon arrival another blood test was undertaken without an abnormal result so the doctor decided not to go ahead with the biopsy.

10. In July 1993 whilst with my husband stationed in Lisburn, Northern Ireland, I found out that I was pregnant. It was a horrible, complicated pregnancy with me having a low-lying placenta. I was in and out of hospital as I kept bleeding but, on top of that, I had the most horrendous itchy rash that covered my whole body and apparently came from my liver!

11. In GRO-C 1994 I had a beautiful girl by Caesarean section. This was my choice as I did not want to go through the trauma of giving birth naturally after what had happened previously. I was in the recovery room when I lost consciousness due to haemorrhaging. I came around several hours later and was told they needed to perform a hysterectomy as the bleeding would not stop. It had to be done and I was just 34 years old. The pregnancy itch instantly disappeared!

12. I bounced back from the hysterectomy and settled into looking after my new daughter. I would however feel tired and nauseous on a daily basis. My body would just ache with pain but I always tried to fight against it. I also discovered that I would itch vigorously if I started sweating. I just wanted my old body back.

13. In January 1995 I watched a Panorama programme called 'Bad blood' and found myself identifying with and agreeing with everything being reported. I said to my husband 'That is exactly how I feel and how I have felt since my own blood transfusion!' We both sat in silence and in shock, contemplating that I might also be infected with HCV.

14. I telephoned my doctor the following day and he agreed that I should go down for a test on an immediate basis but I then had to wait several weeks for the results. The results came back positive for HCV and, at first, I felt a sense of relief that I finally had a diagnosis and I wasn't paranoid after all. The reality of my situation soon set in. My thoughts turned immediately to my family. Could I have passed HCV on to my daughter whilst carrying her? Could I have also infected my older son or husband? GRO-C GRO-C it was a very worrying time and I still now have doubts and demons in the back of my head about it. Before I saw the Panorama programme I had never heard of HCV and didn't really understand what it was.

15. I was referred to a consultant at the Royal Hospital in Belfast and was due to start Interferon clearing treatment. I was on holiday in June so the prescribed drugs started in July. I was admitted to hospital (for what I think was about a week) in order to be shown how to inject myself in the stomach. I was discharged with a pack with details of the drug and helpline numbers to ring about the medication if needed. I lost a lot of weight quickly as the drug was so severe. My dosage was altered and instead of being on the treatment for three months I was on it for longer. I did ring the helpline as I had lost two stone and they agreed it was a huge amount to lose in such a short time. When the treatment ended, I still had the virus!

16. Some time after the treatment had finished, my husband and I were asked to go for a meeting with one of his (female) superiors. The purpose of the meeting was to inform me that she had received a letter from the British Red Cross to say that they believed I had been given contaminated blood during the transfusion. I recall that I had just come out of hospital after a liver biopsy and looked and felt like a zombie. We asked for a copy of the letter but she refused to give us one.

17. In 1997 I was referred to the John Radcliffe (JR) Hospital in Oxford. I attended the JR yearly and I have had a few courses of clearing treatment to Include Interferon, Ribaviran and some other drug which they had to take me

off as it covered me in a red rash. I have also had a few biopsies. I remember there being a very long gap between one treatment and the next because of the lack of treatment options. Every year I attended the hospital and every time I went I would ask them what treatment there was for me. The answer was always the same: 'Nothing that would suit you but testing for new treatment is going on all the time'. This went on every year for approximately 9 consecutive years. In November 2013 I was told I had cirrhosis. Wow! Talk about a shock! I remember the consultant saying to me 'Do you understand what I am saying?' Yes of course I did but I was there on my own and her words to me were like a distant voice. I walked back to my car with my head all over the place. A few miles down the road and with tears streaming down my face I pulled into a layby to phone my husband. I was distraught. He left work and came home.

18. I believe it was due to this outcome that they decided to put me on further treatment in December 2013 but it was horrendous! I had been on the drugs for a couple of weeks and my family really wanted me to go Christmas shopping. I felt awful. I hardly had any energy and I felt so sick with the drugs that I collapsed and ended up in hospital for several hours. After that experience I only left the house to go to hospital for my routine appointments.

19. The damage the drugs do, physically and mentally, stay with you forever. Every time the drugs are administered it takes several months before you can start to rebuild your confidence. To go out for a short walk on your own is a big deal. Later, in 2014, I heard that a guy who lived nearby had found out he had HCV following testing and, within months of him finding out, was given a wonder drug that cured him of the disease! To say I was angry is an understatement. I was livid. At that time, I had just undergone a course of aggressive drugs and still had the virus. I couldn't fathom what was going on with my own treatment. I had lived with this disease for 24 years, had no treatment offered for approximately 9 years, and here was someone who had only just found out but had been immediately cured of it. I felt betrayed.

20. I raised the matter with my consultant at my next hospital visit as I was still upset and angry that I had not been told about this new wonder drug. I really let her know just how I felt and was then offered a placebo trial (albeit I have no idea whether this offer was made because of that conversation). I accepted because I had nothing to lose (except HCV). On 20th April 2015 I got the call to say I was HCV negative. I was clear of the virus.

21. It then took me many months to get used to not having the virus. I still carry the scars of the experience – not just the physical scars of liver cirrhosis but the mental scars.

22. In terms of stigma, no one ever knew I was ill. Only close family and a few very good friends knew what I was going through. I never talked to anyone about it only with those few. After all what would I say to people? People judge. I judge. HIV/AIDS was a big thing as was the stigma that surrounded it. People would think of me and of HCV in the same light.

23. In terms of financial impact, I struggled every day. Throughout the 24 years that I had this virus, I worked (on a part time and full time basis). I was determined that my children have all they needed and that they have as normal a life as I could give them. I always went to bed at around 8.15 pm on a weekday, especially if my husband was away from home. I had to do everything myself as I had no family living nearby. I was never offered help.

24. I struggled with fatigue, sickness, migraine, anxiety and depression. There were times I even nodded off whilst sitting upright at my computer. I would push myself through the day. I remember an occasion wherein I was so ill I had to ask my 13 year old son to go in my place to my daughter's school to collect her. My daughter's teacher actually brought them both home and I remember the look on her face when she saw me. I could see from that look that she knew I was very ill. I remember another occasion wherein I had taken my daughter into town on a bus without being fully alert to the task. I was stunned and at a loss as to how I had managed to leave my bag on the bus and not realise it was missing. When the bus driver knocked on my door

to return it to me, I just stood there looking through him in utter confusion. On another occasion whilst out shopping with my husband in Milton Keynes, I just passed out. I don't know how he got me home.

25. I had to have a lot of sick days from work because of the virus and the treatment. Some companies I worked for paid me sick leave but others did not. I didn't choose to be sick but some days I had no choice but to concede as I was too sick to go into work. I did try alternative medicine that I paid for myself. It made a difference for a while and my bloods showed an improvement but sadly it did not last.

26. I really do not know how my marriage survived. I always say that you can only truly understand what a person goes through if you have the same condition. My husband was my rock throughout all of this and I could never have got through it without his support and that of my family. Even my husband though, as good as he is, didn't really know what I was going through and I say that meaning him no disrespect.

27. It is emotionally conflicting to look upon the person you love and rely on and practically despise them at the same time because they cannot possibly or truly understand what you are going through mentally and physically. You can sympathise and feel for someone but a person can only truly understand the impact of the illness if they have gone through it themselves. It racks me with guilt to feel that way knowing that my husband has done nothing but love me, care for me and support me.

28. In light of the above I find it incredible that someone, somewhere and at some time made the decision not to screen the blood I was treated with or make sure it was not contaminated. Yes, I am lucky because I am still breathing but like thousands of others I am still living a nightmare and will continue to do so for the rest of my life. I was a healthy woman before the nightmare started. What right had someone to take everything away from me?

29. My daughter (having been born in 1994) grew up only ever knowing me to be ill. GRO-C GRO-C GRO-C It haunts me. Every time she is unwell I immediately think about HCV GRO-C GRO-C

30. When I was first told about HCV I could not find ample information about it here in the UK. I actually went on the internet and contacted a clinic in the USA and they sent me information on the virus.

31. I never received any support for my children when they were at school. I paid thousands in childcare expenses.

32. I never received any financial support for my dental treatment and I do believe that my teeth have deteriorated over the years due to the drugs I was prescribed as treatment. My teeth need attention and I might add I am petrified of going to see a consultant about them.

33. In the earlier years, I had no financial support and when I was off work for months while on treatment. I did not receive any financial help while off sick. It was only in later years I received financial help.

34. I cannot get life insurance. As soon as I mention HCV, the insurance companies shut down and don't want to know. I have worked, paid my taxes and have a mortgage but I cannot get life insurance. Why am I, yet again, being penalised and/or discriminated against?

35. I needed a blood transfusion to save my life in 1990 and for that I would be thankful if it was not for the fact that I was given contaminated blood that changed my life forever. I can only speak for myself, but I am sure others can relate to what I have been through as I them.

36. The mental scars are with me forever, never to disappear. Every day I torture myself with the demons of what I have been through and what is yet to come for me now having cirrhosis of the liver through contaminated blood.

37. This has not just affected me but my whole family.

Section 6. Treatment/care/support

38. It takes a lot for me to express what I have been through when I have told so few people. Before this Christmas I had to leave work because I was so overwhelmed. All I wanted was to go home. My daughter couldn't bear to see me that way. When I am suffering it makes her worse and I could see that. I went to my GP and have been referred for counselling but there is a waiting list.

Section 7. Financial Assistance

39. I refer to paragraphs 31 to 33 above. I have never applied for any additional extras and/or grants but I now need dental work urgently.

40. It was only in later years I received financial help in the form of a monthly payment from what used to be the Skipton Fund, now EIBSS.

Section 8. Other Issues

41. There are no other issues.

Anonymity, disclosure and redaction

42. I am not seeking anonymity and I understand this statement will be published and disclosed as part of the Inquiry.

Statement of Truth

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

Signed.........GRO-C.........

Dated ....17.02.20.................