

Witness Name: **GRO-B**

12 FEB 2019

Statement No.: WITN0140001

Exhibits: Nil

Dated: 31 January 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF **GRO-B**

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 November 2018.

I, **GRO-B** will say as follows: -

Section 1. Introduction

1. My name is **GRO-B** My date of birth and address are known to the Inquiry. I am married with four children aged 21, 23, 28 and 31, and I work part time managing my husband's medical practice. I am also a retired nurse.
2. I intend to speak about my infection with Hepatitis C. In particular I will discuss the nature of my illness, how the illness affected me, the treatment I received and the impact it has had on my life and my family.

Section 2. How Infected

3. I suffer from mild Von Willebrand disease, which was discovered at 18 years of age during routine dental surgery, when I had a tooth removed and the bleeding would not stop. This was the first time in my life I had had surgery.

4. I was referred to Haematologist at GRO-B and diagnosed with Von Willebrand disease in 1975. I was asked if I had experienced any other problems with bruising, which I had not, and was told that I would be fine as long as I informed medical and dental staff on future visits that I had Von Willebrand disease, and that I would bleed more than usual.
5. On the 6th of April 1987, while pregnant with my first child, I was admitted to the GRO-B for a planned Caesarean section as I was suffering from preeclampsia.
6. The Consultant, Dr David Newsome, informed me that they were going to give me prophylactic cryoprecipitate before delivery, and for three days following delivery. At the time I questioned this decision as up to this point I had not had any problems with Von Willebrand disease.
7. I was given cryoprecipitate on the 6th, 7th, 8th and 9th of April 1987. Dr Newsome was the first to give it to me on the 6th, and on the following days it was given to me by junior doctors. Every day I questioned why I was being given cryoprecipitate as I felt I did not need it, but was always told 'Just in case'. Each dose was 1 bag of cryoprecipitate.
8. I was not given any advice or further information about the blood product at that time and presumed, as I had been told during my own nursing training, that this blood product had been heat treated as others were.

Diagnosis with Hepatitis

9. Five or six weeks after giving birth I woke up to find my eyes yellow from what I suspected was jaundice. My husband, a doctor, thought that I probably had Hepatitis.

10. We went to the hospital where I was a senior sister and I was attended by Dr. GRO-C **GRO-B**. If it was not for my husband being a doctor I do not believe that I would have been able to be seen at such short notice.
11. My blood was taken to test for Hepatitis. The results took approximately 2 weeks to come back, and showed that my liver function tests were grossly abnormal and an ultrasound confirmed that I had Hepatitis.
12. Dr. GRO-C **GRO-B** conveyed to me in a follow up consultation that there was inflammation of the liver from a virus of unknown origin, but probably connected to cryoprecipitate. At the time Hepatitis C had not been identified and I was told that I had Non-A Non-B (NANB) Hepatitis.
13. As the cause of the disease was still unknown, I was told the inflammation would settle and that the disease would eventually get better of its own accord.
14. The Consultant informed me that I would have to tell other medical professionals that I had Hepatitis. I was married and had one child at this stage, and at no point was I told of the risks of infecting other family members.
15. In 1993 a new Polymer Chain Reaction (PCR) test was introduced for Hepatitis C, and was offered to me straight away. I accepted the PCR test, and was tested for HIV at the same time. Within about two weeks I got the result that I was positive for Hepatitis C, and later I received the result of the HIV test, which came back negative.
16. At this stage there was no treatment available for Hepatitis C.

Section 3. Other Infections

17. I have been infected with Hepatitis C only. I tested negative for HIV.

Section 4. Consent

18. I can confirm that I gave my consent when testing for Hepatitis C and HIV, and for treating Hepatitis C.

Section 5. Impact

Impact of Hepatitis C Virus

19. I was devastated to find out that I had been diagnosed with Hepatitis C, and terrified that my husband had it too. GRO-C

GRO-C

20. By the time I was eventually diagnosed in 1993, I had had two children and was terrified that they had become infected. As I was a Nurse, I had done a fair bit of reading into it and it seemed to be a death sentence, with likely effects being a hepatoma, cirrhosis or liver failure. As a consequence, I suffered from depression.

21. I felt like a leper when having to tell employers and medical professionals of the infection, and the mental effect of being treated differently by anyone who knew of the infection was horrible.

22. Physically, I suffered from tiredness, certain food intolerances and abdominal pain.

Other medical complications

23. As a result of Hepatitis C and Interferon treatment I have been left with Gilbert's syndrome, and suffer from fat necrosis, which has left a crater on my abdomen (from injecting Interferon).

Treatment for Hepatitis C

24. In 1995 and around two to three weeks after giving birth, I was selected to take part in a clinical trial and research project for Interferon, which I accepted. This was at the Edinburgh Royal Infirmary.

25. They performed a liver biopsy and laparoscopy to see if I was a suitable candidate, and the Consultant came to let me know I could start the trial.

26. I was confined to a side ward and told that I was not allowed to have my new-born baby with me to ensure she did not contract Hepatitis C as I had intravenous drips, nor was I allowed to breastfeed. When I asked about the breastfeeding the Consultant informed me that at the time they were unsure of the risks of transmission.

27. I was put on an 18-month course of Interferon, which involved injecting myself three times a week, starting around 3 months after giving birth.

28. I began to feel the side effects immediately, which were an overwhelming feeling of the flu, extreme tiredness, an intolerance to certain foods and a constant feeling of aches and swollen joints all over my body.

29. This was extremely difficult mentally and physically for me for a number of reasons. I was at the time looking after three young children, and due to the treatment I could not spend as much time with them as I wanted, and what time I did spend with them took a huge physical toll on me. I was also depressed thinking that I would feel like this for the rest of my life.

30. Within 8 months I had cleared the virus. The consultant insisted that I continue and complete the full 18-month course to be safe, which I did. I feel very lucky that I happened to be in Edinburgh at the right time, and that they were looking for potential recruits.

Treatment by others

31. From the very beginning, when people discovered that I was infected with Hepatitis C I was treated differently, especially in hospitals and at the dentist, as I had to inform them of the infection.

32. On the one occasion that I went to a dentist for routine treatment they told me that they didn't have the experience to deal with blood borne viruses and as a result could not take me on as a patient. I was not happy about this but I understood that there was a lot of hysteria and ignorance about the disease.

33. I did not go back to a regular dentist and had to receive any dental treatment at the hospital, however even there I was treated very differently because of the disease.

34. Doctors and nurses would wear extra gloves, gowns and masks when attending me, and there were specific policies used in hospitals for treating people with blood-borne viruses, such as using visors, wearing thicker gloves and treating me in a side ward away from other patients. Separate instruments were held back for use on infected patients.

35. When in the hospital for dental work I was always put to the end of the list as a 'dirty case' and the theatre would be cleaned straight after I had been treated in it.

36. The worst example of treatment happened on the 16th of August 1995 when I was admitted to Edinburgh Royal Infirmary to give birth to my third child by Caesarean, before I had been accepted as a patient there as we were new to the area. The Edinburgh Royal Infirmary was at the forefront of Hepatitis C research and as a result had to process many cases of infection. I was treated twice – once in the obstetrics ward as an outpatient and then again when I was admitted to give birth. On both occasions I was put into the same category as drug addicts and prostitutes, and was asked various probing questions about my drug intake and sexual history.
37. I burst into tears both times, but was assured that these were routine questions, and when I asked why I was being asked the same questions twice I was told that there were two sets of notes: one for the hospital and one for the midwife.
38. Despite being first on the list, I was moved to the bottom because of my infection. I arrived in the morning, having not eaten since midnight because of the Caesarean, and was starved until 2pm when I was eventually allowed to give birth and then eat. Mine was a high-risk pregnancy and the theatre had to be 'fogged', or sterilised, and when I entered there were around 10 people present, all of them wearing extra protective clothing against my disease.
39. I had an epidural and so was conscious throughout the birth, and in hindsight I wish I had been given general anaesthetic as I was treated like a plague victim. General anaesthetic was an option but, being number one on the list, I thought I would be in and out quickly.
40. Even now I still suffer from medical professionals wanting to play it safe and re-test me for Hepatitis C, despite testing negative for 23 years and research suggesting that I am clear.

41. At age 60, I was offered a colonoscopy [GRO-B] and again had to jump through the same hoops in having a blood test to confirm I was negative, and again having to answer questions about drugs use and my sex life. They even mentioned that they would use the 'dirty scope', which was reserved for people with HIV, even though I have documentation proving I am negative, which is highly infuriating.

Impact on Family and Social Life

42. I was constantly worried about how my diagnosis would affect my marriage, and shortly after finding out, I was scared that I could have infected my husband. I was told that I could pass the disease onto him sexually, and was advised by a bacteriologist to only use barrier contraception.

43. Whilst on the treatment I was depressed as I felt so ill and scared that I could pass the disease on to my husband or my children, which added a lot of stress to my marriage and my family.

44. As I had already given birth to two children since finding out about my diagnosis I was very worried that I could have passed the disease on to them, made worse by the fact that at that time there was no treatment available.

45. When I started the Interferon A treatment I also had to raise three young children, [GRO-C] which meant that I wasn't capable of being as active a parent as I had wanted because of the side effects of the treatment. It was so strenuous that my parents had to come and live with us for two months to support the family.

46. [GRO-C] also suffers from Von Willebrand disease and shares the same genotype as me, and I have been worried since my diagnosis that [GRO-C]

would be given cryoprecipitate after a fall or a cut and become infected
GRO-C I put myself on a medical trial with the sole aim of proving that that treatment on the trial, the antidiuretic hormone vasopressin, would work for
GRO-C now carries a card instructing that in an emergency **GRO-C** only be given vasopressin and not cryoprecipitate.

47. When my youngest daughter was born the Consultants wanted to use her for research purposes to determine if Hepatitis C could be transmitted during pregnancy. I consented to them taking a blood sample from my new-born baby before and after the umbilical cord was cut, and allowed them to take the cord to use for further tests. When my daughter was older we were honest with her about this, and why she was not breastfed, causing her to worry about it being passed to her either hereditarily or at birth.
48. Most of my friends were from work at the hospital and as a result were sympathetic towards me, however I could not tell my extended family for fear they would not understand.

Impact on My Career and Finances

49. When I was diagnosed with Hepatitis C I was working in intensive care, and had been planning to continue in this with the hope of eventually moving into teaching. As there are strict policies in place regarding working around open wounds, blood, drips and arterial lines, I was unable to continue working in intensive care and was forced to abandon these plans.
50. Whilst on the treatment I was unable to return to work more than part time because of fatigue and other symptoms, and was only able to work nights. When the treatment had finished after 18 months we moved as a family to **GRO-B** where I was left alone to recover and also care for my child **GRO-C**
GRO-C and was unable to return to work at all.

Section 6. Treatment/Care/Support

51. I have never had any problem in accessing treatment, and count myself very lucky that both my husband and myself work in the medical profession, otherwise I feel like I would not have had the same opportunities.
52. I understand that because of the stigma and lack of information available at the time, medical professionals were hot on HIV and Hepatitis; however, it is extremely frustrating that even to this day I have to take extra blood tests despite them always coming back negative, and I feel as though 'Once a leper always a leper'.
53. I do not believe that at any point I was offered counselling or psychological support for my infection, and to an extent feel as though I was in blissful ignorance of the full effects that Hepatitis C would have on the lives of my family and me. If I had been offered counselling I feel that I would have refused it.

Section 7. Financial Assistance

54. I had no idea of any funds or trusts until a Haematologist **GRO-B** Dr Chris Mattock, wrote to me in the early 2000s to inform me of an advert in the Journal of Haematology which asked for doctors to refer eligible patients to the Skipton Fund.
55. Dr Mattock sent me the application forms, helped me to fill them in and sent them off to the Skipton Fund on my behalf. The application process was straightforward and took a couple of months to complete from filling out the application forms to receiving the money. I received £10,000 in a one-off payment.

56. Whilst the application was pending, no further documents and information were requested. As far as I am aware there were no preconditions to me qualifying for the Skipton Fund.

57. Skipton followed this up with by paying me a £300 monthly flat rate, which I did not apply for. I am still receiving this support.

58. I received further correspondence from Skipton alerting me to extra support if I had suffered cirrhosis of the liver.

Section 8. Other Issues

59. I feel extremely lucky to have the connections I do in the medical profession, without which I do not think I would have received the treatment I did, where I did.

60. I would like to know why more was not done to track down those who the NHS knew could have been infected. I would also like to know why nothing was done once the authorities knew that some of the blood was infected.

Statement of Truth

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

Signed

GRO-B

Dated

8th February 2019.