Witness Name: GRO-B
Statement No.: WITN2082001
Exhibits : WITN2082002-05
Dated: 2nd April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

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

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B 1978 and my address is known to the Inquiry. I live with my parents GRO-B GRO-B and have two children with my ex-partner, but I only care for my children at times. I intend to speak about my experience of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me and my family.

Section 2. How Infected

2. I suffer from moderate to severe haemophilia A. This is also known as Christmas disease.

3. Currently, my haemophilia is treated with Benefix. I cannot remember the names of any other products that have been used to treat my haemophilia or the year when I changed to Benefix. I think I might have changed to Benefix on this side of the millennium. I think in the past Factor IX might have been used to treat my haemophilia, but definitely not Factor VIII.

4. In the early days, I was treated mostly at the Sick Kids Hospital in Edinburgh. I have also been treated at the old Royal Infirmary of Edinburgh, the new Royal Infirmary of Edinburgh, GRO-B GRO-B, and my GP GRO-B GRO-B GRO-B.

5. I think I became infected with hepatitis C in the early 1980s, when there was a CJD and AIDS breakout that came out for haemophiliacs. My mum and dad enquired about this and it must have been between 1981 and 1983, when blood products from America where imported that came from prisoners who were infected with these kinds of diseases. I believe that is what happened. I would say that it is one thing hearing that I had hepatitis C and another very different thing trying to comprehend that as a teenager. I do not think that I tried at the time to understand how it happened, when it happened and I was not asking many questions that I could have asked, as I was aged 14 or 15 and just wanted to go out with my friends and lead a normal life.

6. When I was young, I could maybe not go to hospital at all for a period of three months and have to go three or four times a month. I have been treated at hospitals for as long as I can remember.

7. I do not believe that any information was given to my parents beforehand about the risks of being exposed infection from blood products.

8. I found out that I was infected with hepatitis C when I received a letter from the Edinburgh Royal Infirmary saying that there was a chance I might have hepatitis C and that I should get tested. It turned out that I did have hepatitis C. I think I was 14 years old at the time and I was 15 by the time that I started treatment.

9. I was provided with information about the infection by Dr Hayes and Dr Denis. Dr Hayes is the liver specialist and it was the first time that he was involved in my treatment. He broke all the information down into layman's terms. I was told that the hepatitis C was a disease that affected the liver and that it could lead to scarring or cirrhosis of the liver. I was advised not to think of it as an alcoholic's disease. The effects and treatment were also discussed. That was pretty much it. It was explained, but at 14 you do not appreciate the seriousness of the illness. I went to see Dr Hayes with my mother. I believe there is a letter from Dr Hayes regarding our meeting. I produce a copy of this letter in evidence and refer to it as **WITN208202.**

10. I would say that I was given adequate information to help me understand and manage the infection day-to-day, but being a teenager I never realised the severity of the disease and just put that information to the back of my mind in order to be able to get on with my life.

11. I think that information should have been provided earlier. If they turned round and said that it was in the early 1980s when I became infected, then I do not understand why it took a further 10 or 12 years to pass before I was told. I think that somebody knew that the blood was infected.

12. My views and opinions about how the results of tests and information about the infection were communicated is that the results were quite conclusive and so was the information as to my liver functions and the infection. I do think it is indelicate the way that a letter was sent to me indicating that there might be a chance I was infected with hepatitis C and advising to get tested. It would have made things better if this had been explained face-to-face rather than with the letter asking me to come in for an appointment.

13. I was provided with information about the risks of others becoming infected as a result of my hepatitis C. I was told that open wounds constituted a risk that the infection could be passed on, and there was also a risk regarding unprotected sex and cuts. I was also told not to share toothbrushes. I think this was explained quite well and I was told if I sustained any cut to pre-warn other people that I had hepatitis C and advise them not to get near me.

Section 3. Other Infections

14. I was only infected with hepatitis C. I think at some point I was told there was a risk of CJD, but again I think this must have been checked and it must be fine as I do not recall ever been tested for it. There is evidence on my medical records that I was a risk of vCJD. produce this letter in evidence and refer to it as **WITN208303.**

Section 4. Consent

15. I would like to say that I have never been treated or tested without my knowledge, without my consent, or without being given adequate and full information, but the truth is that I do not know. There were a couple of times when I have felt like I was being used as a guinea pig. Any time that I went over to hospital, there was always a need to take blood and there were always an extra couple of vials being sneaked onto the tray. Being young and naive, I never bothered to ask.

Section 5. Impact

16. The mental and physical effects of being infected with hepatitis C didn't really sink in until my first course of treatment. A couple of weeks into the treatment, I started to notice the severe side effects. For three months, I was down and not like a normal teenager should have been. I was embarrassed about this. The injections were very sore. I had to get one injection three times a week on my stomach, and it was extremely painful. I would have them at night and then go to sleep. It was like having the worst flu and as soon as I started to feel slightly better, I had to do it all over again. On Saturday I was normally recovering from Friday's injection and Sunday was the only day I really had to myself. I also experienced awful weight loss and lost about one or two stone in three months. Before I started the treatment, I never really had any physical effects, I just knew that there was something there in the background, but didn't bother with it as just like with haemophilia, I simply had to get on with it. It wasn't until I started treatment that all the mental and physical effects appeared.

17. I would not say that I have developed any further medical complications or conditions as a result of the hepatitis C. My liver functions are normal although at some point I did experienced mild inflammation of the liver.

18. I have been on two courses of treatment to treat my hepatitis C. The first one was when I was aged 15. This treatment was just an injection, interferon. The second treatment was when I was aged 28. This was an injection of interferon and ribavirin tablets.

19. I was on each of these courses of treatment for three months and then blood was taken. It had been decided that if the treatment was making a difference, then I would continue for the full six months. If the treatment was not making a difference, then I would stop. Neither of my treatments was successful and I was only on them for three months each.

20. My second treatment meant that I had to take three tablets a week and just one injection a week instead of three.

21. The treatments might have caused memory loss as I now have to write things down all the time or else I forget. I also experienced complications with my teeth, but I believe this is as much due to the haemophilia as it is to the hepatitis C.

22. Although my liver functions are normal, I have not been tested in a couple of years and no tests have been offered on a regular basis, only when I have attended hospital for an appointment. There would be no way of knowing just now if it has become worse and my liver is becoming affected. If I asked for a test of my liver functions, I hope that it would not be denied.

23. I would not say that I have ever faced any difficulties or obstacles in having access to treatment. After my second treatment, I was told that I would have to wait until new treatment was available. Two years ago, I received a telephone call from my GP telling me about a new treatment that apparently had a 100% success rate. I was offered an appointment to discuss. At the time, however, I thought that I was healthy and happy enough and the treatment would make me ill for

months, so I decided not to go. I am a little bit pessimistic and I am not sure that I believe that the treatment really has a 100% success rate.

24. I do not believe that there were any treatments which should have been made available but were not. I remember Doctor Hayes saying it was likely that a new treatment would be available that did not include interferon. There is a letter in my medical notes to this effect. I produce this letter in evidence and refer to it as **WITN208204**.

25. The treatment had a severe mental and physical impact on me. When I was younger, I did not really understand what kind of illness I had until I started the first course of treatment. The side-effects were horrendous and I realised that what I had was serious. Receiving the injections was very painful and I was physically sick very often when I was on the first treatment. This did not happened when I was on the second course of treatment as my body accepted it a bit better the second time around, but I still lost three stone in three months. However, I still managed to do my job as the side-effects of the second treatment were not as bad.

26. I would not say that becoming infected with hepatitis C had has had any impact on any other medical treatment. I do have to be seen by special dentist who has to be made aware of the hepatitis C, but I did attend the same dentist before the hepatitis C as well. For minor operations, it is the same procedure and I have to attend a special haemophilia or blood disorder specialist, who again has to be made aware of the hepatitis C. One time that I attended the dentist, when I went into the room it looked like a crime scene because everything was covered in white bags and everybody was covered from head to toe. This was shortly after they were told about the hepatitis C and I thought it was odd.

27. I would not say that I do not feel and any kind of stigma as a result of becoming infected with hepatitis C because my friends have been supportive and so have the people who I have been involved in a couple of relationships with before my ex-partner. When I explained to my ex-partner that I was infected with hepatitis C, if anything, it brought her closer to me. I do not think that hepatitis C has had a huge impact on my private and family life other than my memory loss. My family are all supportive and they do not treat me any differently. As I got older, I became more aware of the risk to my liver and there have been a few times when I have chosen not to go on nights out in order not to drink so that I would not damage my liver. I would say that I do not go out as much. The last time I had a drink it was for my 40th birthday GRO-B. Otherwise, I never drink because I value my health too much.

28. I would not say that becoming infected with hepatitis C had any sort of impact on my education or career. I cannot recall if at the time of my first treatment I had to take time off school or if I had just left school.

29. Becoming infected with hepatitis C has not had an effect on my work. I did not require to take time off work for my second treatment.

30. I have always been unable to get life insurance and travel insurance is extortionate. I had a joint mortgage at one point with my ex-partner and this didn't affect me, but I think that is more to do with my ex-partner being a staff member of the bank.

31. My family had to look after me when I was younger, in my mid-to-late teens. During treatment, it was like my mum and dad had an infant all over again. They had to be running after me with buckets as I kept being physically sick.

Section 6. Treatment/Care/Support

32. Counselling or psychological support was never offered to me as a result of becoming infected with hepatitis C until recently. I received a letter from the haemophilia centre informing me that they had appointed a psychologist and a psychiatrist to support people with inherited bleeding disorders. Although, there is no mention of people who contracted hepatitis C as a result of receiving contaminated blood product. I produce a copy of this letter as refer to it as **WITN208205.**

Section 7. Financial Assistance

33. I think I have received financial assistance from the Caxton fund. cannot remember the names of any other Trusts or Funds.

34. I received £20,000 when I was 25 and £30,000 in 2016. Currently I have been getting monthly payments of £1,500 since October 2018. I think that this is due to my haemophilia and liver.

35. I cannot remember how I found out that financial assistance was available.

36. I cannot remember much about the process of applying for financial assistance. I think that I must have applied myself and then asked for help to fill in the forms. It was my mother who helped me.

37. I do not think I have faced any difficulties or obstacles in applying for and obtaining financial assistance.

38. I do not think that there were any preconditions imposed on the making of an application for, or the grant of, financial assistance.

39. My opinion about the financial assistance system is that it is great that there are things in place to help people like myself and others that are less fortunate. The amount that I received per month is more than adequate and I am grateful for it.

Section 8. Other Issues

40. I have not been involved in any campaigning or litigation as a result of becoming infected with hepatitis C.

41. I do not think that I was involved in the Penrose Inquiry either, and I did not give a statement. However, I did get newsletters and other information about the Penrose Inquiry.

42. I am happy for my statement be public and do not wish to remain anonymous.

Statement of Truth

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

Signed GRO-B

Dated 1/7/19