

Witness Name: Mrs Elizabeth Green

Statement No: WITN1249001

Exhibits: WITN1249002

Dated: November 2018

## INFECTED BLOOD INQUIRY

---

### FIRST WRITTEN STATEMENT OF MRS ELIZABETH GREEN

---

I, Elizabeth Green will say as follows:-

#### Section 1. Introduction

1. My name is Elizabeth Green. My date of birth is GRO-C 1953 and I live at GRO-C with my husband, Mr Daniel Green. We are both retired. I have one daughter and three grandchildren.
2. 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

3. I have severe Von Willebrand's disease and I was diagnosed in the first few years of my life. Both my parents were carriers of Von Willebrand's disease. GRO-C has Von Willebrand's disease but it is very mild.

4. When I was a child I was in and out of hospital all the time as there was little treatment available. The first time I was given blood products was in the early 60's. I was originally given cryoprecipitate and then I moved onto Factor 8 (FVIII) in the late 1970s. I was given FVIII about once a month in the hospital and soon after I started having FVIII at home.
5. I was treated at The Royal Free Hospital (TRFH) under the care of Professor Tuddenham and Professor Christine Lee. I had also attended Milton Keynes Hospital (MKH) and I was under the care of Dr Miller.
6. I am not sure when I was given infected blood products (FVIII) however, in or about the late 1970s or the 1980's I started to suffer from constant nausea, so I believe I must have been infected around this time.
7. I also remember around the same time that Dr Heathcote from the liver department of TRFH came to my childhood home and asked if I had flu like symptoms and they mentioned something about Hepatitis non A and non B. I cannot remember the full conversation that I had. No further information was given in relation to this.
8. No information or advice was given to me about the risks of being exposed to infected blood products. The hospital just told me that FVIII was a new drug. It was great as I was able to administer FVIII at home. I also thought FVIII was great because the volume that I was given was three times smaller and my time spent in the hospital was reduced.
9. I believe I was infected with Hepatitis B (Hep B) and Hepatitis C (Hep C) as a result of being given infected blood products (FVIII) in or about the late 1970s or the 1980s.
10. In 1980, after my daughter was born, I recall a conversation in relation to HIV with Dr Goldman. I recall Dr Goldman saying that I should not have anymore children as there is a risk of being infected with HIV. I was very upset when I got home as I would have liked another child. I was also

very frightened with the possibility of getting HIV as other haemophiliacs were testing positive and dying.

11. I found out in or about March 1981 that I was infected with Hep B. I had been unwell at this time. I had been feeling itchy, my urine had changed colour and I was yellow around the eyes, so I went to the TRFH and had blood tests. I was seen by Dr Goldman at the TRFH. I previously worked in microbiology at TRFH so I was aware of the symptoms for Hep B. When I got to the hospital I went straight into an isolation room and they took some blood tests and confirmed I had Hep B. I cannot remember the conversation that I had with the doctors about this. I just remember being told that I had Hep B and all the medical staff seemed surprised at my positive result.
12. If I was tested before 1981 for Hepatitis then no one told me. I had a lot of blood tests and I assumed most blood taken was for routine blood tests and clotting tests for Von Willebrand's disease. There is a possibility that they tested me for Hepatitis, but I was not told about it.
13. I was tested for HIV on the 11/04/1985, 19/03/1986 and 12/05/1987. Please refer to the attached exhibit **WITN1249002**. I was surprised that I was not tested for HIV prior to 1985. No one told me that I would be tested for HIV. I was again tested for HIV on the 25/07/1987 and the test was negative. Again I did not have any knowledge that I was being tested for HIV. I was again tested for HIV on the 06/11/1987 and again I was not told that I was being tested. A further blood test for HIV was carried out on the 15/03/1990, but I was not told about this. I was never told that they would be testing me for HIV. I cannot ever recall a conversation with the doctors or nurses confirming that they will test me for HIV.
14. In or about the early 1990s, I found out I had Hepatitis C (Hep C). I was sent a scrap piece of paper through my letter box informing me I was Hep C positive. I did not know I was being tested for it or that my previous blood tests were going to be used to test for Hep C.

15. When they sent me the piece of paper, which stated that I was Hep C positive, I was not provided with any further information as to how dangerous the infection was or what treatment was available. I did not do my own research then because in those days it was never made clear to me how dangerous Hep C could be. I initially thought it was a mild problem as no information was given to me.
16. I was only given adequate information for Hep C when the doctors realised how serious it was, but this was approximately ten years after I had been infected. I do recall Dr Miller talking to me about possible treatment that is available, which I initially declined. I believe information should have been provided to me earlier.
17. In or about 2006, I did my own research about Hep C. I then found out that a lot of people had also been infected with HIV as a result of the infected blood products. At this point, I still had no knowledge that I was being tested for HIV.
18. I was told about the Hep C in a very circumspect way. It was truly shocking that I was told via a scrap piece of paper that was posted to me. They should have at least sat me in a room and told me face to face. I have had cancer a couple of times and you would not expect them to send you a piece of paper stating you have cancer.
19. I was not told about the risks involved in relation to infecting others. GRO-C

GRO-C

### Section 3. Other Infections

20. I have no idea if I was infected with any other infections as a result of being given infected blood. No advice was given in this regard.

21. However, there is a letter in my medical records from TRFH dated 18/02/2009 in relation to vCJD and providing some information about the risks of vCJD. I do recall receiving this letter. I believe it asked if I wanted to know if I had ever received FVIII which had come from someone who had gone on to develop vCJD. I responded that I did not wish to know. I did not wish to discuss the possibility at any time since then.

#### **Section 4. Consent**

22. I was tested for Hep B, Hep C and HIV without my knowledge, consent and without being given full or adequate information. When I was working in the GUM clinic in MKH in or about 2006, I saw a list as long as my arm for HIV tests that they had carried out on me. I was never asked to sign anything and I did not know that they were testing me for HIV. I always thought this was odd because at the GUM clinic you had to sign a consent form to give your consent before they could test the blood. I do not recall giving written consent for any blood tests for HIV.

23. I knew I was being tested for Von Willebrand's disease and it should have been for clotting tests and routine tests e.g haemoglobin, LFTs but any other research that they did I did not consent to or have knowledge of.

#### **Section 5. Impact of the Infection**

24. The mental effect of being infected with Hep C and B was that it made me feel so unclean. I feel shame and embarrassment despite it not being anything that I could have prevented. I did not tell anyone for years. I was only able to speak to my husband initially and eventually I had the courage to tell my two very close friends. When I received the scrap piece of paper informing me that I was Hep C positive I was apprehensive, but I was not overly worried at the time as I did not realise how bad the infection was.

However, as more information about Hep C became available, I got more and more worried. I started looking on the tainted blood website and it frightened me how ill people were becoming.

25. Coupled with a perception of being 'unclean' and the stigmatisation of both HIV and Hep C, I believe this has alienated haemophiliacs from justice and our standing with the general public.

26. I suffered from nausea and I was always tired and I believe this was as a result of being infected with Hep C and B. Ultimately these side effects were the reason that I had to leave work.

27. The physical effects of the Hep B were that I suffered from nausea and my eyes had discoloured. I attended hospital in relation to this, but I was not given any treatment.

28. I do not consider that I have suffered from further medical complications as a result of Hep B and C. My liver results have been consistent, so I have been lucky.

29. After doing my own research I started treatment for Hep C in or about March 2017. I was given Viekirax plus Exviera plus a low dose of Ribavirin. I was very sensitive to the Ribavirin tablets. The doctors therefore reduced the Ribavirin tablets. I was on Ribavirin tablets for approximately 8 weeks and then I had to stop as I was unable to continue with the treatment due to the side effects I had. Please refer to paragraph 31 of my witness statement.

30. I do not consider I had any difficulties accessing the treatment. I purposely waited several years for the treatment for Hep C because I knew that the earlier treatment for Hep C, (Interferon) could last years and consisted of daily injections and might not have worked. I therefore did not want to entertain it.

31. I was informed by Debra Pollard, lead nurse at the haemophilia centre that I was one of the last patients to get treatment in relation to Hep C at the Haemophilia Centre. I am not sure if this was age related. This was when the new treatment was introduced.
32. Physically, the treatment for the Hep C was horrible, especially for the first couple of months. I had nausea, headaches, stomach pain, muscle weakness, indigestion, a lot of burping, tiredness, poor appetite and burning sensation in my body. I therefore stopped the Ribavirin but carried on with the rest of the treatment for three months. Luckily, when I finished the treatment, my symptoms started to ease.
33. My infected status has had an impact on my medical care. In or about 2002, I attended hospital for a colonoscopy procedure. I had my own special colonoscopy equipment at the hospital because I was infected with Hep C. When I went in for my procedure the hospital staff were unable to find my colonoscopy equipment and they would not use another set of equipment to start the procedure. This made me very angry because I had been through a lot of preparation prior to the procedure. The procedure did not go ahead.
34. My infected status also impacted me when I had a tooth removed at TRFH in or about 2000s. The dentist who came in looked like he was wearing a space suit, covered head to toe. It was very over the top. I felt quite offended by this.
35. I found it quite upsetting when my medical file had 'infected Hep C' on it. My wrist band was also marked with 'Hep C'. Everyone in the hospital was able to see that I was Hep C positive.
36. I have not told anyone other than my husband and my two close friends that I had Hep C. I could not speak to anyone due to the stigma that was attached to it. I was concerned that if I told people that I had Hep C they

would think I was a drug abuser or something similar. People had weird ideas for example if you touched them, they would become infected.

37. A few years ago I went to see my local MP to speak him about the Contaminated Blood Scandal. I told him that I was infected with Hep C and he physically took a step back. I felt quite offended by this. He did not help in anyway. It did put me off about going to speak to people about this because of his reaction.

38. I finished school by the time I was infected so my education was not affected. However, I feel that my employment was affected at one stage at TRFH as a result of being infected with Hep C. I never told anyone at work that I was Hep B and C positive. I did not even tell them I suffered from Von Willebrand's disease. I just did not want anyone to know because I was worried about their reaction. I had a very good relationship with everyone at work and I did not want that to change.

39. I also believe I lost out on a job opportunity at one point because I was infected with Hep B and C. I applied for a different position in the hospital and I believe I was not given the position due to being infected with Hep B and C. As previously stated I had to give up work because I was utterly exhausted and was unable to cope. This was hard because I enjoyed working and I liked the people I worked with. I believe that had I not been infected with Hep B and C, I would still be in employment.

40. I lost my salary when I had to give up work, and this was worrying at the time as I had concerns that I would not be able to cope. The travelling to and from the hospital for my treatment is a financial burden as it was costing me a lot of money.

41. The biggest impact this has had on my family was that GRO-C  
GRO-C We found this very difficult to deal with at the time.



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

42. Approximately 5 years ago, I had been offered counselling through the Caxton fund. I declined this because from what I read you would contact them over the telephone and I did not want to do that. I was not offered any other counselling. I consider that if I was offered counselling it would have helped. My family and friends were very supportive and I think with their support it eased the situation that I was in.

## **Section 7. Financial Assistance**

43. I found out about the Skipton fund by reading about it in the newspaper. I received £20,000 as a lump sum payment in the late 1990's. I receive approximately £300 a month and payment for this started last year. I also get a top up as I only get a pension. My top up was originally £200 a month which started three or four years ago but when my husband got his state pension it decreased to £134. I now receive the monthly payments from EIBSS.

44. The paper work for the initial lump sum from Skipton was relatively straight forward. I applied to Skipton and they sent me some paper work which I then forwarded to Professor Christine Lee. Applying for the top up payment was a lot more complicated. I had to fill in a lot of paper work which was not a nice thing to do.

45. I think it is very unfair that the money I do receive is means tested. I was infected with Hep C and I therefore consider the same amount should be given to everyone. It is embarrassing and soul destroying.

46. I also applied for a session of reflexology, which they agreed to but it was so humiliating applying for it and as a result I did not ask for the reflexologist or any other treatment ever again. The paperwork that was sent to the reflexology had their logo all over it and they did not pay for my sessions until months later. This is a fund that is meant to help people, but it has done the complete opposite. It was excruciatingly embarrassing.

47. I was hopeful when it became the EIBSS. I was hoping it would become easier to apply but I believe it has become more difficult.

### Section 8. Other issues

48. My Hep B tests results seem to have been redacted when I saw the nurse last year at the hospital. When I went for a follow up appointment last year whilst having treatment for Hep C, I did mention to the nurse that I had Hep B in the past. The nurse did not see anything in my notes regarding Hep B so she said she would test me again. When she did test again apparently the results came back negative. She told me that there was no positive anti-bodies which means I have never had Hep B, but this is impossible. [GRO-C]

49. I also want to mention the scandalous selling of plasma to Bain Corporation, an asset stripping company, who have since sold on to a Chinese company. This occurred just a few years ago when contaminated blood was very much on the political agenda. You would have thought after all the horrors of infected blood this would be the last thing they would do. I do not know how they got it passed through parliament, but they probably thought it was a convenient way of washing their hands of any future contamination issues. It makes me sick to my stomach.

50. I also want to mention that I was very shocked and angry at both Professor Christine Lee, Professor Tuddenham and Professor Kernoff for giving me infected blood products. [GRO-D]  
[GRO-D]  
[GRO-D] Professor Christine Lee was heard laughing on a recording and she said, 'I think they are just after the money'. I have had an awful lot of doctors and she is the only one that I felt was very cold towards me.

**Anonymity, disclosure and redaction**

51. I confirm that I do not wish to apply for anonymity and that 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 25<sup>th</sup> November 2018.

## Medical Summary

(This summary is not intended to exhaustive but sets out key points in the records relevant to the statement)

### Virology Results

24/03/1981	HBs AG positive Clinical data – HBs AG positive in February
27/10/1983	Hepatitis B 1991 HBs AG Neg
12/05/1987	HBs AG – Negative Anti-HBs – Positive
25/07/1989	anti HIV – Negative
06/11/1989	anti HIV – Negative Hep B surface antigen: negative Anti HBs >30
15/03/1990	VCA IgG – positive Anti HIV – Negative
30/01/1991	Hep B surface antigen – Negative HIV – Negative Hep B Surface Antibodies – Positive Hep C antibodies – Negative

25/11/1991	Hep B surface antigen – Negative HIV – Negative Hep B Surface Antibodies – Positive Hep C antibodies – Positive
03/02/1993	Hep B surface antigen – Negative HIV 1 or 2 antibodies – Negative Hep B Surface Antibodies – Positive Hep A antibodies - Negative Hep C antibodies – Positive
15/04/1994	Hep B surface antigen – Negative HIV – Negative Hep B Surface Antibodies – Positive
29/10/1996	Anti Hep C Virus – Positive
24/02/1997	HCV – Positive
24/02/1997	Hep B surface antigen – Negative HIV 1 or 2 antibodies – Negative Hep B core Antibodies – Positive Hep B surface Antibodies – Positive Hep A antibodies - Negative
17/02/1998	HIV – Negative HCV – Positive Hep B surface antibodies – positive Hep A Antibodies – negative

14/08/00 Hep B Surface Antibodies – Negative  
Hep A Antibodies – Positive

Significant Entries/Absent Entries

25/08/1978 Letter to Dr Tuddenham from Mario Abela, Senior Registrar - Bleed into the right wrist on 16 August 1978. Treated with 10 packs of cryoprecipitate (approximately 700 units) and prescribed analgesia. She responded well to this treatment.

31/01/1979 Letter to The Controller from Eleanor Goldman – she had been issued with medical supplies, including syringes, needles, freeze-dried concentrate, sterile water and analgesics. These are necessary for her treatment and should be allowed to accompany the patient wherever she goes.

09/05/1980 Nursing notes – time: 23.00 – 1000u FVIII injected IV

10/02/1981 Nursing notes – treated with 500 units of FVIII, small bleed

13/02/1981 Nursing notes – treated with 920 units of FVIII

07/08/1981 Nursing notes – Treated with 2,000 units FVIII at 10.45am. Pre & post levels taken. Blood transfusion, FVIII given PM

08/08/1981 Nursing notes – treated at 10.30am with 2,000 units FVIII pre & post levels x HB taken.

09/08/1981 Nursing notes – FVIII given at 10.30

10/08/1981 Nursing notes – treated with 1000 units of FVIII at 11am

11/08/1981 Nursing notes – treated with 1000 units of FVIII at 10.00

12/08/1981 Nursing notes - treated at 9.15 with 500 units of FVIII

13/08/1981            Nursing notes - treated with 500 units FVIII

14/08/1981            Nursing notes – treated with 500 units FVIII

05/12/2007           Letter to Professor Tuddenham from Dr Miller – Hep A antibody detected, Hep B core antibody detected, HIV antibody negative. 'Elizabeth also has mildly abnormal liver function, presumably related to her Hep C.

26/03/2008           Patient information sheet – vCJD Risk – Hep C Positive – It appears that she has chronic Hep C without signs of advanced liver disease...

18/02/2009           Letter to Patient from Haemophilia Centre – information about vCJD

28/04/2010           Letter to Dr Ho Yen from Dr D Patch – she is hep c treatment naïve. I am pleased to say that her FibroScan result suggested a very low risk of fibrotic Liver disease and she is more than happy to no consider antiviral therapy.

20/08/2010           Letter to Dr Ho-Yen from Dr M Hamilton, Consultant Physician & Gastroenterologist – investigations summarised.  
Previous Hep B  
Hep C infection

06/12/2010           Letter to Dr Ho-Yen from Dr M Hamilton, Consultant Physician & Gastroenterologist – investigations summarised.  
Previous Hep B  
Hep C infection

09/03/2011           Letter to Dr Yee from Dr Miller (Milton Keynes Hospital) – diagnosis: chronic Hep C infection, previous Hep B infection – '.....understandably she is disappointed by the department of

health's reluctance to pay compensation for patients infected with Hep C through blood products'.

- 07/06/2011 Letter to Dr Saunders from Dr M Hamilton, Consultant Physician & Gastroenterologist – investigations summarised.  
Previous Hep B  
Hep C infection
- 12/08/2016 Letter to Dr Canthaboo from Dr Yee - ..... 'she is being monitored for her Hep C and may receive anti-HCV therapy in the future'.
- 09/03/2017 Letter to Dr Canthaboo from Dr Mandal – 'since commencing on HCV treatment with Viekirax plus Exviera plus low dose of Ribavirin 200mg twice a day, she has had Ribavirin relating side-effects of nausea, headache, stomach pain, muscle weakness, indigestion, a lot of burping, also complained of tiredness and poor appetite and burning sensation in the body.  
  
From the second week of treatment, she started to feel better. I think she is very sensitive to Ribavirin table. Therefore, we plan to reduce Ribavirin if her haemoglobin dropped down. She informed me that she has had past Hep B infection. Therefore, I requested hepatitis surface.
- 18/05/2017 Letter to Dr Canthaboo from CNS Meena Ju - ..... 'while on treatment, she had various side effects which were relating to Ribavirin.  
  
Ribavirin was stopped when she was week eight on treatment, but she responded very well with treatment. HCV RNA not detected within four weeks on treatment and today blood tests show HCV RNA not detected.
- 10/08/2017 Letter to Dr Canthaboo from CNS Meena Ju – '.... Blood tests today show HCV RNA not detected.