Witness Name: GRO-B
Statement No: WITN1675001
Exhibits: WITN1675002-7
Dated: DECEMBER 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B

GRO-B will say as follows:-

Section 1. Introduction

1. My name is GRO-B My date of birth is GRO-B and I live at GRO-B with my wife, GRO-B; W I am by occupation a retired plumber/heating engineer.

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.

3. My wife, GRO-B: W has also provided a Witness Statement to the Inquiry under Witness Number GRO-B

Section 2. How Infected

4. I have mild Haemophilia A. I was diagnosed with haemophilia when I was 13 years old. I had a tooth extraction that kept bleeding after the procedure, so I was sent for tests.

5. I was treated at the Oxford Haemophilia Centre at the Churchill Hospital under the care of Dr Paul Giangrande. I was only ever received Factor VIII (FVIII) on a maximum of four occasions, once for a severe back injury and the rest for tooth extractions. I do not remember exactly when I was given the four doses of FVIII. The medical notes and records I have received are incomplete. The documents I have are vague and inconsistent on the issue as reflected in the medical chronology at the end of this statement.

6. I am infected with the Hepatitis C Virus (HCV).

7. I do not remember much about how I was informed of my HCV diagnosis because of the passage of time but I believe that I was told that I was HCV positive in July 1995. I do not remember anyone telling me face to face. I do however remember making a telephone call to the hospital to ask what HCV was, as I had no idea. I do not remember to whom I spoke. I refer to a document at **Exhibit WITN1675002** which I believe to be a hospital record of that telephone conversation. The document bears the date of 20th July 1995. I also refer to a document at **Exhibit WITN1675003** being a 'Hepatitis C Checklist' dated 17th July (corrected from June) 1995, bearing a signature that looks like 'J Trowell'. I do not recall a discussion with Dr Joan Trowell or anyone else on any of the topics ticked at that time.

8. I subsequently received a letter from Dr Giangrande advising me that I had tested positive for HCV and suggesting I attend a meeting with Dr Joan Trowell 'for advice and management'. A copy of that letter dated 16th August 1995 is referred to at **Exhibit WITN1675004**. I also refer to **Exhibit WITN1675005** being

a copy letter from Dr Giangrande to my GP Dr GRO-B dated 7th September 1995 indicating that it is likely that I was infected with HCV in March 1978, the date of my first FVIII treatment.

9. I refer to **Exhibit WITN1675006** being my UKHCDO Patient Record. Given Dr Giangrande's view that I was infected through administration of my first ever dose in March 1978, it would appear that I was infected with the product 'Oxford FVIII'. However that assumption is at odds with speculation by Dr Trowell that I was first treated in 1970 or 1973 and later by Dr Collier that I was probably infected in 1973.

10. No information or advice was ever provided to me before being treated with FVIII about the risk of being exposed to infection from blood products.

11. I now refer to **Exhibit WITN1675007** being a hospital record of matters of concern raised by me at a Hepatitis B vaccine appointment on 17th August 1995. In addition to trying to understand and come to terms with the HCV diagnosis, I had concerns about my wife and daughter and whether they were infected. My wife was tested for HCV by my GP and her (positive) HCV result was forwarded to the hospital ahead of a pre-arranged appointment we had with Dr Trowell a short time later.

12. I remember the appointment with Dr Trowell that I attended with my wife. At that appointment Dr Trowell addressed my wife about her positive HCV test result. Dr Trowell asked us if we had had extra marital relationships and was very offensive to my wife.

13. I should have been informed much sooner of the HCV diagnosis and as soon as the doctors knew. Dr Giangrande's letter sent to me on 16th August 1995 appears to infer that he knew about the positive result before my routine review appointment the previous month at the Haemophilia Centre. I refer again to **Exhibit WITN1675007** noting that my GP was also unhappy about the delay by Oxford Haemophilia Centre in informing him of my positive HCV result. I had to

ask for help and advice about HCV, rather than that help and advice being delivered to me in a timely way. There was also some delay for us in waiting for my wife's test results.

Section 3. Other Infections.

14. I received a letter on 20th September 2004 saying I was also at risk of vCJD. To receive that letter was a shock and another concern for our family. The hospital cannot tell me anything more than that I am 'at risk'. They will not know whether I am in fact infected with vCJD until I have died.

Section 4. Consent.

15. I have been tested without my knowledge and consent on many occasions. I did not know I was being tested for HCV and did not know what it was. I was just notified that I was HCV positive.

16. I have been tested for HIV on at least two occasions. I had no knowledge of this until I received my medical notes in July or August 2018 and read the documents evidencing that I had been tested negative on two occasions.

17. I have consented to testing for research purposes whenever I have been asked because I want to help others.

Section 5. Impact

18. HCV has left me with serious health issues. I have developed cirrhosis of the liver and attend ultrasound appointments every 6 months to monitor for further liver deterioration. I have an enlarged spleen. I have esophageal varices. I have type 2 diabetes and hypertension. I have type 2 cryoglobulinemia vasculitis and atrial fibrillation placing me at risk of stroke and heart disease.

19. I was first offered clearing treatment in or around 2004 as some scarring to my liver had been identified at that time. I did not feel particularly unwell at that time. I was concerned about the side effects of the treatment. My daughter was getting married and my wife and I were moving. It was not a good time to embark upon 48 weeks of gruelling treatment. I could not afford to get ill.

20. I had an endoscopy in 2006 because I was then experiencing severe stomach pains. It was confirmed that I had developed varices. Despite the clear need for an endoscopy investigation, the hospital was at first hesitant to proceed because of the vCJD risk. There was a delay whilst the hospital made the arrangements deemed necessary to accommodate me.

21. I started the HCV treatment in 2007 under the care of Dr Collier at Southampton Hospital. I took ribavirin tablets and injected myself every Friday with pegylated interferon over the entire 48 weeks except for one week when I was advised to stop because of my platelet count. I was still working as a plumber at that time and would try to get through the week as best as I could but all the time dreading Friday when I would have to take the next injection. I was really unwell and I felt like what I would describe as a zombie. I felt tired and fuzzy, I had headaches and could do nothing for the entirety of the weekend. I was barely able to go to work on a Monday. The blood test result taken just one week after the treatment had finished, confirmed that I was still HCV positive. I was given no assurances as to what would happen next except that I would have to wait for the next new treatment.

22. I did not get a second attempt at clearing the HCV until around 5 years later. I was then back in GRO-B In 2012 or 2013 I had a 26 week course of interferon/ribavirin and boceprevir. The side effects were as bad as before. My vasculitis worsened. Again, the treatment was unsuccessful.

23. The third and final clearing treatment was a combined harvoni and ribavirin tablet twice daily over the course of four weeks. I was told that the treatment was very expensive and I had to wait several months to find out whether or not the treatment would go ahead or not. The Heptology Nurses had to plead my case at a meeting and then an application had to be made to NHS England for funding. The application was approved subject to NICE criteria that it should stop at four weeks if I was not responding. My chance of clearing the treatment hung in the balance. The treatment at the end of 2015 was successful.

24. I am left with chronic fatigue in addition to all the health problems I have as detailed at paragraph 18. My quality of life is significantly impacted. I get up in the mornings feeling ready to start the day only to feel exhausted half way through the morning. I have been unable to work for 5 or 6 years. I have become depressed as a result.

25. My wife and I have not told anyone (including our own family) about our HCV diagnosis. We do not think it fair that they should be burdened with the knowledge. We only told our two children when they had reached adulthood. We wanted to protect them and ourselves.

26. There is a lot of stigma surrounding HCV. People are ignorant and quick to condemn you if they know you have HCV. They think you are an alcoholic or a drug addict. At best they look at your differently. Some people think that if you have HCV you have HIV.

27. As I am unable to work, I am financially reliant upon my monthly EIBISS payments and my wife's salary.

28. My wife and I could not get a mortgage for a long time. We are unable to obtain life insurance. We managed to purchase our first home in GRO-C At that time, I felt well and had no symptoms. We were turned down by a lot of high street

lenders and went through a financial advisor who found a mortgage lender on a repayment basis, but at a higher premium than we would have otherwise paid. When I could no longer work, my wife and I decided to downsize which was a shame because my wife loved our home and we would not have moved otherwise.

Section 6. Treatment/Care/Support

29. I had to wait for five years between the first failed treatment and the second treatment. It was an onerous amount of time to be left without a treatment option. The funding issues surrounding my third and final treatment created unnecessary worry and stress for me. I felt like I had been made to beg for the treatment I needed.

30. I have never been offered counselling or psychological support.

Section 7. Financial Assistance

31. I received a Stage 1 Skipton Fund payment of £20,000 in or around 2004 as did my wife.

32. I was unable to obtain the Stage 2 Skipton Fund payment until 2015. Until then Dr Jane Collier (Consultant at the Churchill Hospital, Oxford, Dr Joan Trowell had retired) said that I did not meet the 'Stage 2 criteria'. The two biopsies I had had did not apparently demonstrate that there was sufficient liver damage. I thought this strange because at all my hospital visits, I was told that I had cirrhosis of the liver. I had to push her to apply on my behalf and the application was successful.

33. I receive monthly income payments from EIBSS, formerly through the Skipton Fund.

Section 8. Other Issues

34. Notwithstanding my serious health issues, my chronic fatigue, low mood and inability to work anymore, I have tried to get on with my life. HCV is a part of my life and I have to get up each morning, the sun still rises and the dog still needs walking. To some extent I feel like W and I are the lucky ones as we are still here whilst others have not been so lucky. We are angry that this scandal has gone on for so long without answers.

Anonymity, disclosure and redaction

35. I am seeking anonymity and would like my Statement redacted before publication. However I understand this statement will be published and disclosed as part of the Inquiry. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

Sign GRO-B

Dated 14th JANUARY 2019

Medical Summary

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

1970	Haemophilia diagnosis.
	Speculation as to first FVIII treatment *(Letter Dr Trowell to Dr Neale dated11/10/1995)*
1973	Speculation as to first FVIII treatment *(Letter Dr Trowell to Dr Neale dated11/10/1995 and Dr Collier to Dr Neale dated 24/05/2001)*
1978	Speculation as to first FVIII treatment *(Letter Dr Giangrande to Dr Neale dated 07/09/1995)*
	Date of first FVIII treatment *(UKHCDO Patient Record)*
01/10/1986	Hospital record '2nd HIV blood test'.
27/05/1987	Hospital record 'Blood test HIV'.
10/02/1991	Hospital record 'HIV negative on 2 occasions'.
07/1995	Notified HCV positive
20/07/1995	Hospital record that 'PT phoned concerned about Hep C results', 'GP in unhappy at OHC delay in informing him of Hep C result'.
16/08/1995	Written notification of HCV diagnosis *(Letter Dr Giangrande to patient)*
17/08/1995	Hospital record of conversation with patient about his HCV diagnosis/concerns
20/09/2004	Written notification patient at risk of vCJD
2007	First clearing treatment pegylated interferon and ribavirin
2012/2013	Second clearing treatment interferon, ribavirin and boceprevir
2015	Third clearing treatment harvoni and ribavirin