

ANONYMOUS

Witness Name: **GRO-B**

Statement No: WITN3252001

Exhibits: None

Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF **GRO-B**

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

Section 1. Introduction

1. My name is **GRO-B** I was born on **GRO-B** 1946 and I live at **GRO-B** with my wife. We married on the **GRO-B** I am a qualified biochemist and worked as a civilian in the Police before I retired.
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 in respect of my wife **GRO-B: W** who was infected with Hepatitis C (HCV) through contaminated blood products. **W** has provided her own witness statement to the Inquiry (Witness Number **GRO-B**).
3. This witness statement has been prepared without the benefit of access to all my wife's medical records.

Section 2. How infected

4. [W] was born with type 2B Von Willebrands disease. She was classified as a '*moderately affected patient*'.
5. [W] was treated at Manchester Royal Infirmary Haematology Department from around 7 years old until 1973 when she then moved to [GRO-B] North Yorkshire where she was under the care of the Haemophilia Unit of Harrogate Hospital (subsequently closed) and at the same time under the care of the Haemophilia Unit of St James University Hospital Leeds, which she still attends. She was under the care of Dr Swinburne, Dr McEvoy, Dr McVerry and then Dr Horne.
6. [W] was first treated with snake venom before cryoprecipitate and Factor VIII concentrate (FVIII) became available. According to her medical records cryoprecipitate was then given to her for the first time at the St James Hospital Leeds Haemophilia Unit in December 1974 when three teeth were extracted. [W] believes she received infected FVIII on the 21 September 1982 as she was coughing up blood so the hospital believed she was hemorrhaging. In total, [W] believes she received FVIII on at least 6 occasions.
7. [W] was never warned of any risk associated with blood products.
8. [W] was infected with HCV as a result of being given contaminated blood products.
9. [W] found out she had Hepatitis in November 1982. There was no mention of Non A Non B hepatitis, the doctors just simply called it '*Hepatitis*'. It was only when she was about to have an operation on the 17 June 1991 that she was told that she had HCV.
10. We were not provided with any advice in 1982 to help understand or manage the infection. Nobody ever came and warned [W] to avoid alcohol or fatty

foods. [W] should have been provided with advice on how to protect her liver as soon as the information was available.

- 11 [W] was given no advice in 1982 (when she was first infected with Hepatitis) about sexual transmission to me or transmission by touch or proximity either. I was first tested for HCV in 1991. This test was luckily negative. I was not aware of this HCV test at the time. In 1991 I was then given advice about sexual transmission. By then my wife and I had been having sex for years without protection.

Section 3. Other Infections

- 12 [W] was informed that she could be at risk of contracting Variant CJD (vCJD).

Section 4. Consent

- 13 [W] was tested for HIV in May 1985 without her consent. [W] was also tested for Hepatitis B multiple times without her consent.

14. I was not aware that I was being tested for HCV in 1991. If they had asked for permission to test me I would have agreed but I was not given this choice.

Section 5. Impact of the Infection

15. At the time of her original Hepatitis infection in 1982 [W] had Pneumonia, Bronchitis and Pleurisy. Her medical records include a letter, dated 18 May 1983, six months after she was infected, from Dr Swinburne, Director of the Leeds Haemophilia Unit to Dr McEvoy, the Harrogate Consultant Haematologist. The letter states that [W] was found to have a thrombocytopenia (lower platelets); and also states that "*I hope this is temporary*" but she still has thrombocytopenia.

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- 16 [W]'s liver has become damaged as a direct result of the HCV [W] also now has Bronchiectasis with occasional bleeding from the lungs coming up into the throat, which developed gradually from when she was infected. The Bronchiectasis was getting gradually worse and worse until about 1990, when it was finally diagnosed. [W] had an operation in 1991 to remove part of her lung, which alleviated the symptoms, but she still has Bronchiectasis and takes antibiotics and nebulised salt every day to control the disease. I believe that this Bronchiectasis may have been caused by the HCV.
- 17 [W] also now has high cholesterol, low thyroxin Level and low vitamin D levels, which may or may not be due to her HCV.
- 18 [W] was offered HCV clearing treatment in 2009 and 2012 but she declined the treatment on both occasions. The first time was because she did not feel well enough and the second time was because she had heard horror stories about the considerable side effects. Also having low platelets due to the thrombocytopenia was a problem as the 2012 treatment may have further reduced her platelets to a dangerous level.
- 19 [W] cleared the HCV in 2016, following a course of Sofusbuvir and Ribavirin between March 2016 and June 2016. [W] was tested in June 2017 and July 2018 and she showed no signs of HCV.
20. All of [W]'s lab results were immediately labelled with 'HIGH RISK' after she was told she had Hepatitis in 1982 but she received no advice till 1991 about alleviating her hepatitis or about the disease.
- 21 [W] was more tired after 1982 than before. Therefore, we have had fewer holidays than we would have done. Some holidays had to be cut short or we did not do as much sightseeing as we would have done normally. There is no point sight seeing if you're too tired to enjoy it. If you feel under the weather there is no point. Our social life was affected because we would leave events

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early. If we left early we would not be open about why we needed to leave. We had to make excuses.

22. In 1984 the government had posters saying '*bang, bang you're dead*' which caused people to be terrified. Nobody knew if AIDS was contagious. I know of people who caught HIV through sexual contact and died. There are 300 houses in our village and information does seep out. With the best will in the world a secret will get spread. The less you tell people the better.

23. I was under considerable stress as I worried that **W** could die from liver cancer or chronic liver cirrhosis due to her Hepatitis. I also worried that she could be reinfected with a stronger dose of more virulent Hepatitis, AIDS or with vCJD from receiving additional blood clotting products. I understood that fatal liver disease could arise very quickly, at any time, and with few warning signs. I believed that a liver transplant would not be possible with **W**'s condition and even if she had one that it might either not succeed or might only sustain life for a limited period. I have given her care and support, when she has been ill.

24. In November 1999 I went from a very well paid job at Yorkshire Water and applied for a less well paid, less responsible, less busy job with less overtime so that I would have more time available and be better placed to care for **W** and support her if she became extremely ill. I accepted voluntarily redundancy even though the company wanted me to stay. I did this because I used to leave at around 7.30am and get home at around 7.30pm. I travelled all over Yorkshire in my job. I wanted a '*9 to 5 job*' so I could be there for **W**.

25. I started working for the police as a statistics performance manager. I worked there for 11 years. It was about 2/3 of the salary so I had to take a cut in salary. I used to get home at around 6.00pm though and could more easily have time off to look after **W**.

Section 6. Treatment/care/support

26. Neither [W] nor I were offered care or support or counselling.

Section 7. Financial Assistance

27. In about 2003 or 2004 we were involved with an American law firm, Lieff Cabraser Heiman & Bernstein in a Litigation case involving pharmaceutical companies supplying American blood products. However Lieff Cabraser Heiman & Bernstein wrote to us on 8 December 2004 stating that because St James Hospital, Leeds and Harrogate Hospital had refused to supply details of the brands and batch numbers of blood products given to [W] in the 1970s, 1980s and 1990s, she could not show that she had used American blood, so they could no longer act as our attorneys and could not prosecute any claim on our behalf. Therefore we were not involved in the litigation from December 2004 and [W] did not receive any compensation.

28. [W]'s mum saw on the news that the Government were giving compensation to people infected with HCV and HIV from contaminated blood products. I then decided to ring the Haemophilia Society to see if this was true. I was assured that it was and was told to ring the Skipton Fund who then provided us with documents for [W]'s doctor to complete.

29. We then received a £20,000 lump sum. [W] had to sign a waiver to receive this lump sum payment stating that we would not sue the NHS or the government.

30. In December 2016 we also started receiving monthly payments which they back dated to April. Since 2015/2016 [W] has received a winter fuel payment.

31. There is other support which was available but this was means tested. My salary and pension meant our household income was above the threshold, so we did not apply.

Section 8. Other Issues

32. Leeds NHS Trust did not send all of [W]'s medical records. We originally asked for records between 1973 to 1996. All the records we received were from the year 2000. There was a single sheet saying early records were in 'overflow'. After a lot of pressure, they sent more records over a 4 month period but there is still about 7 years missing from the time of her infection. I think they have been destroyed.

Anonymity, disclosure and redaction

33. 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.

34. 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.

Signed.. [GRO-B] ..

Dated.. 26/08/2019 ..