

ANONYMOUS

Witness Name **GRO-B**

Statement No: WITN1535001

Exhibits: WITN1535002/4

Dated: July 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** **GRO-B**
GRO-B
GRO-B

2. I was infected with Hepatitis C (HCV) as a result of being given contaminated blood products.

3. **This witness statement has been prepared without the benefit of access to my full medical records.**

Section 2. How infected

1. I suffer from Haemophilia A classed as mild. I was diagnosed when I was about 3 or 4 years old. I was playing outside and cut the back of my head after climbing trees and it wouldn't stop bleeding and I was taken to the local hospital where I was diagnosed.

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2. My first treatment was with snake venom which was injected straight into the open cut. I understand the doctors told my parents told that I should be 'wrapped in "cotton wool" However, I said to myself "I am not rapping myself up in cotton wool'. I remained active and had a lot of bleeds in the joints. This had no effect at the time however as I have got older I have had issues with these joints.
3. Over the years I have been treated at the Royal Cornwall Hospital (formally known as Tresliske Hospital) Truro, Derriford Hospital Plymouth, The Royal Devon and Exeter Hospital Exeter, I have also attended the GRO-B GRO-B The Churchill Haemophilia Unit in Oxford and the GRO-B Hospital, Southampton and the Royal Free and UCL in London
4. I have had a good and close relationship with Dr. Rizza and Dr Matthews at the Churchill Haemophilia unit whom I started seeing when I was 17 years old.
5. I have been under the care of Professor Rosenberg (Consultant Hepatologist) for the past 16 years and have followed him around the country to stay under his care. For example, I lived in Devon and also; and have travelled up to Southampton just to see him. We have a lot of trust in him; he treats us as people rather than hospital numbers. When you find a Consultant like him you don't change.
6. I am not exactly sure when I was infected with HCV, although I believe it was between the 1970s - 1980s possibly when I had 3 teeth extractions in the 1970s or general bleeds or the operation to remove a sebaceous cyst in the 1980s or when I had my tonsils removed. My first positive test I am aware of was in the late 1990s at GRO-B I visited my GP because of extreme fatigue and he carried out a blood test. He did not tell me he was going to carry out a HCV test.

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7. When I received the positive result I wasn't given much information or advice by my GP other than to be careful with open wounds, and any blood spillage and not to drink alcohol. He also asked if I drank a lot. There was no advice on sexual relations. My GP was very unsympathetic and I had to use my common sense and extrapolate information from different sources: I phoned the Haemophilia unit in the Churchill Hospital and the Haemophilia Society to find out more. A lot of people were giving minimal information.
8. I cannot identify the specific date or place I was infected however I believe it must have been either the Churchill Haemophilia Centre or the Churchill Hospital. I used to be under the care of Dr. Rizza and Dr. Matthews however more recently it has been Paul Giangrande and Dr. Keeling.
9. According to the UK National Haemophilia Database (NHD) records; I have been treated with many different blood products originating from the US and the UK. Such as Oxford FVIII, Cryoprecipitate, Recombinate, Hemofil-M and Kogenate, Advate and RE-Facto AF I have also received Desmopressin Sub Cut (15mcg/ml). I refer to my HND records at Exhibit WITN1535002.
10. I believe that the HND records are not a complete record of all my treatments as there is a letter from the Oxford Haemophilia Centre dated 19th October 1976 stating I was treated "with daily injections of Factor VIII" and there is no record of this on the HND records. I refer to exhibit WITN1535003. I also believe there are documents missing from my medical records.
11. I was given no information or advice beforehand that there was any risk of being exposed to infection from the blood products given to me.
12. I was given no information or advice on how to manage and reduce the risks of the HCV infection. I believe full and detailed information should have been provided a lot earlier.

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13. I should have had a warning from the Churchill Hospital as soon I tested positive for HCV. The GP was less than helpful and avoided giving answers. I was forced to be proactive.

Section 3. Other Infections

14. I believe I have been exposed to the risk of being infected with vCJD as I have received a letter from the NHS saying a blood donor who may have contributed to the blood products I have received later developed vCJD.

Section 4. Consent

15. I have been tested without my knowledge, consent or without being given adequate or full information as I was not told by my GP that I was being tested for HCV and as there is an entry in my medical records on the 12 July 1999 saying "Repeat Hep C bloods" which seems to imply I have been tested previously. I refer to Exhibit WITN1535004 I also believe I have been tested for the purpose of research.

Section 5. Impact of the Infection

16. When I was first diagnosed with HCV, the opposition from my GP to continue to refer me to a long standing treatment centre in Oxford caused me great psychological stress and anguish. The GP was very unsympathetic and obstructive.

17. In or about July 2001 I took part in a trial of the use of Pegylated Interferon and Ribavirin conducted under the care of Dr Cramp at Derriford Hospital I was put on a 12 month course. The HCV virus was rendered undetectable during the treatment however shortly after the treatment finished it reappeared. This was extremely psychologically devastating. This treatment had a huge effect on me; I became aggressive. My GRO-B has said she did not recognise the person I was during the treatment.

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18. In or about 2004 I took part in a second trial; this time under the care of Professor Rosenberg at Southampton Hospital. This consisted of a 12 months course of Pegylated Interferon. As before, the virus was rendered undetectable during the treatment; reappearing once the course had stopped. This was another crushing blow.
19. I stuck with Professor Rosenberg; who put me on a long term Interferon course of between 2-3 years. I understand this was in order to protect my liver from the HCV virus. No one knows the long term effects and Professor Rosenberg says I have had the longest sustained period of Interferon treatment he knows of.
20. Finally in 2015 I took part in a third trial; again under the care of Professor Rosenberg but this time at the Royal Free Hospital, London. This was a triple drug course; which consisted of Ribavirin, Daclatasvir and Sofosbuvir. This cleared the virus finally in January 2016 after a 3 month course.
21. I have had to live with the knowledge I had the HCV for over 20 years. This was like a death sentence hanging over my head which has caused enormous psychological stress and pressure. Some of the side effects during the trials caused severe changes in my personality and nearly caused the break down of my marriage.
22. This infection has caused great disruption to my life, coupled with the inevitable strain of having end stage liver cirrhosis. Stress, worry and uncertainty have littered the last 20 years for me and my family, especially in the knowledge that many other sufferers have died. The emotional trauma experienced at each stage of testing and the continued concern about an increased chance of liver cancer still affects me to date.
23. It has not just been the HCV infection which has caused medical issues. I have developed type 2 diabetes, high blood pressure, glaucoma and suffered from gallstones. I have also developed a nervous shake in both hands which

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makes writing and holding a drink very hard. I believe all these effects are the result of either the HCV infection or the treatments.

24. The effects of the treatments ranged from fatigue to extreme mood swings. I was unable to carry out everyday tasks and the physical work which was needed around the property we lived in. The stress of constant monitoring and anguish whether the treatment would work; could be a cause of my high blood pressure. At the time I ran a bed and breakfast with my wife which was physically demanding.

25. Regarding the stigma associated with a HCV diagnosis. As Haemophiliacs we put up with a lot of prejudice in the 1950s. Sometimes the contaminated blood subject comes up in conversation and we would look at each other and not mention it. We did not mention it at work as it could have been detrimental to finding a job. I have had to hold back on conversations and steer them away from the topic. The 1980's smear campaign didn't help and created an instant association with HIV and Haemophiliacs. People still look at you differently e.g. receptionists at a hospital. This has the affect that you keep the information to yourself and live everyday trying to keep the secret.

26. My infection had no effect on my education as it was contracted after I finished. It had some effect on my work. I struggled to hold my attention for long periods and experienced extreme fatigue. At the time my wife and I ran a bed and breakfast and holiday cottages which was physically demanding.

27. With regards to the financial affects, my wife and I have suffered greatly due to me being infected with HCV. My wife and I owned our dream house and grounds in Devon. We had holiday cottages in the grounds and ran a bed and breakfast in the house which was physically demanding. Once we knew, everything changed drastically. The property and grounds were too large for us to continue to run. We had to sell the property which meant we gave up our sole income as my wife would not have been able to handle the property if I died and I was feeling too fatigued to cope with the work load. My father in law helped us out and we stayed at his for 2 years on no income and with all

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our belongings in storage. We had to prepare for the short term as we didn't know how long I had to live. This caused a massive upheaval in our lives with the financial repercussions still felt today.

28. My wife and I have had to travel extensively to receive treatment at various Hospitals, in Oxford, Southampton, Plymouth London. This was performed at very frequent intervals and has involved a massive amount of mileage and hotel stays; which I funded myself.

29. When going to hospital my wife and I were usually away for a couple of days at a time and my elderly father-in-law who was then living with us had to be left on his own. He had Parkinson's and was prone to falling over. In the end It proved too dangerous to leave him on his own we so eventually he had to move into a home. We couldn't afford the standard of care we wanted for him.

30. Being diagnosed with HCV influenced my decision to take a lump sum of half my pension pot because I did not know if I would live much longer.

31. My [GRO-B] has put my needs, and helping me, first which has been vital [GRO-B] helped me so much after the first trial failure when I was very low. My diagnoses with HCV and end stage liver Cirrhosis has radically changed our everyday lives. My [GRO-B] has had to follow a strict hygiene regime especially when dealing with any spilt blood on clothes etc, everything had to be disinfected.

32. Our marital relations were also [GRO-B]
[GRO-B] not to be tested herself as this would affect her obtaining insurance, so she was left in ignorance for many years and that has also been a source of stress and worry. My [GRO-B] was finally tested when an effective treatment for HCV was found and fortunately was negative. My [GRO-B] is a deep thinker and I know she has been affected [GRO-B] worries whenever I go to the hospital or to see a consultant and I always get a call.

Section 6. Treatment/care/support

33. We experienced an obstructive GP, Dr. GRO-B. He blocked my attempt to go to Oxford for treatment as he wanted us to go through the local trust. I had to go to my MP who then wrote to the local health authority. The issue was sorted out 2 years later when a new head of Hematology started at the Churchill Hospital and authorized the extra funding for my treatment.
34. I have never been offered any sort of psychological support or counselling as a result of receiving contaminated blood.
35. I have not experienced any problems in obtaining dental care. As stated above I had 3 bouts of tooth extractions in the 1970s to remove all teeth. The only issues are due to the cirrhosis, diabetes, and high blood pressure and it can be a difficult balancing act to get the medication right.
36. When I went for cataract surgery; the nurse didn't know what Haemophilia was and my GRO-B had to advise on the pre and post op injections and precautions. During a routine eye examination the nurse double gloved and made a scene of my infected status. Regarding the most recent cataract operations I was told the operation was at 12:30 pm, so had the Factor VIII at 10:30 am. The nurse mentioned I was last in the queue and so I told her the level of Factor VIII will decrease with time. I had to go back and speak to the consultant. You cannot rely on the professionals to communicate and it has been a fight from day one.
37. The closest we have got to support is through Professor Rosenberg who has become a friend. Initially we had to wait for 4 hours to see him but when we met him we knew he was the doctor for us. I can call him up at any time and ask as many questions as I want. It's wonderful and reassuring to know someone still cares.

Section 7. Financial Assistance

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38. I heard about the Skipton Fund from the DOH and I received from the Skipton Fund the stage 1 payment of £20,000 in September 2004 and stage 2 payments of (£25,000) in November 2004 and £25,000 in April 2011. We have been receiving a heating allowance since 2004. Presently this is about £530. We have never been awarded any support or grants to cover our travel costs or hotel costs.
39. The process of applying for me was pretty straight forward and easy. We did not encounter any difficulties or obstacles in applying for the payments. The only preconditions set were means testing. I believe this should not have been the case; we were given this and should be compensated like any other injured person.

Section 8. Other Issues

40. The Inquiry should be moving faster as the number of people infected/affected are dropping as a result of dying. There is no reason in my view why the government shouldn't properly finance this and double their team looking for documents and reviewing them. I feel, (and many others feel the same) that civil servants are dragging their feet. There is an equal importance between putting monetary awards and accountability. We want closure; I still walk out and don't know when it will hit me, and how that will affect my wife and family? Money doesn't always solve the problem.
41. The whole thing stinks and it always has done. I see bereaved mothers, fathers and children and they haven't had half the compensation we had. Not everyone is like us and proactive. They are trying to buy our silence through increasing the benefits marginally, however that doesn't make up for the physical, mental and emotional impact of being infected. Everybody should be given the opportunity to have closure. I can tell you this problem will not go away.

Anonymity, disclosure and redaction

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42. I want to remain anonymous and do not wish to give oral evidence

Statement of Truth

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

Signed..... GRO-B

Dated 16th July 19
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