

ANONYMOUS

Witness Name: GRO-B

Statement No.: WITN0304001

Exhibits: WITN0304002 - 3

Dated: 27 05 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 8 February 2019.

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

**Section 1. Introduction**

1. My name is GRO-B. My date of birth is GRO-B 1947 and my address is known to the Inquiry. I have three children (one daughter and two sons) and also grandchildren. In GRO-B I married my second husband ("husband"), who is the GRO-B. I am now retired but used to be employed as a GRO-B and later ran my own GRO-B GRO-B.
2. I intend to speak about my infection with the Hepatitis C virus ("HCV") which I contracted as a result of a blood transfusion after a minor gynaecological operation in 1981. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family.

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3. I confirm I have chosen not to be legally represented and the Inquiry team has assisted me with my statement.
4. I confirm I would like to remain anonymous for personal reasons.

### **Section 2. How Infected**

5. On 28 January 1981 I had a minor gynaecological procedure at GRO-B GRO-B on GRO-B After the procedure, it was discovered I was bleeding. I had a serious complication and was taken back to the theatre. I had a hysterectomy and received eleven pints of blood through transfusion.
6. I do not recall the names of the doctors who treated me but I know they were very concerned at the time. My husband later told me the GRO-B had telephoned him at home in the middle of the night and asked him to come in as soon as possible because I might not make it through the night.
7. After the surgery, I remained at GRO-B for approximately one week. I was then offered a stay in a convalescent home, but I did not want to go. I remember wanting to get back to my children who were GRO-B GRO-B at the time.
8. I decided not to sue GRO-B for what happened to me. Mistakes happen and I am grateful to be alive. I was told that a very high percentage of people who have blood transfusions die within the first year and I have always felt lucky. If I had not received the blood then I would not be here. However, as a result of the blood transfusions, I believe I was infected with HCV and this is about infected blood.
9. In the years following the surgery and transfusions I felt very tired and unwell. I tried to get on with my life despite feeling this way. At the time, I thought the way I felt may be due to the side-effects of having a hysterectomy at such a young age. Furthermore, I was a mother raising

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three children, I was overweight and working part time. I assumed these factors might have all contribute to how I was feeling.

10. On 1 December 1995, I received a letter from the National Blood Transfusion Service. It explained they were in the process of testing all previous blood donors for the HCV. They identified that as a result of the blood transfusions I received in 1981, I may be infected with the HCV and invited me contact them to arrange a blood test and discuss things further **[WITN0304002]**. It came with no prior warning and was a tremendous shock.
11. I remember I telephoned the National Blood Transfusion Service, asking if I could leave the test until after the Christmas holidays as it was not what I needed at that time of year. I was told I needed to come in as soon as possible so I would have the results before Christmas. I travelled GRO-B miles from my home to attend Addenbrooke's Hospital in Cambridge for a blood test and meeting. I met with a doctor who explained that at least one of the bags of blood I received was from a donor who may have been infected with the HCV. I was provided vague information about how the United Kingdom had purchased blood from America and it had come from odd places such as prisons.
12. The results came back quickly and I was told my blood tested positive for the HCV. I recall having to inform Addenbrooke's Hospital I had been a blood donor as they were not even aware. Only then did they check back through my records. Fortunately, I had only given small amounts of blood as my veins did not work very well and I had to eventually stop donating. I was still very worried that I could have infected others.
13. On 22 January 1996 my General Practitioner and I received letters from the National Blood Transfusion Service confirming the positive HCV result **WITN0304003 - WITN0304004** and proposing I be referred to a Hepatologist at Addenbrooke's Hospital. My letter offered an apology for the recent 'oversight in sending you a routine invitation to give blood'. The letter

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to my General Practitioner stated the blood transfusion I received may have been infected with the HCV.

14. In terms of telling me about the risk of infection earlier, I suppose the National Blood Transfusion Service had to go through a lot of people and so I am not sure how much sooner I could have been told. However, from the start of this ordeal, the way the information about my infection was communicated to me could have been better. It should have come from my General Practitioner or someone I knew. Instead, it came out of the blue from a Service I did not know.
15. When I was diagnosed, internet searches were not available and you could not find things out about the infection as you can today. I did not know much about the HCV at all and I do not believe I was given adequate information to understand and manage the infection or any support.
16. I was not provided with adequate information about the risks of others being infected as a result of my infection. I thought it was poor they did not know I was a blood donor and think they should have checked when they identified me.

### **Section 3. Other Infections**

17. To the best of my knowledge, I do not believe that as a result of being given infected blood products I have contracted any infection other than HCV. I am lucky it was not the Human Immunodeficiency Virus.

### **Section 4. Consent**

18. I have been asked if I believe that I have ever been treated or tested without my knowledge or consent and the answer is no, I have always consented to the tests and treatments I received. Everything Addenbrooke's Hospital did was up front and the information provided was adequate.
19. I do not recall the year, but after my diagnosis there was research into HCV which I consented to and was happy to be a part of. When I attended



Addenbrooke's Hospital I saw a researcher who took some blood. I never heard about the results of that research.

**Section 5. Impact**

20. The mental and physical effects I have suffered as a result of being infected with HCV have been very difficult. The infection has caused great physical and psychological damage. At first, I never knew why I felt tired and unwell. I became quite depressed after I was diagnosed. I had three children and was concerned I would be gone before they had grown up. I used to get a lot of aches, pains and other issues.
21. Further medical complications and conditions have resulted from the infection. After being diagnosed, I developed Tinnitus, which I was told could be caused by stress and anxiety. Over the years the Tinnitus will return if I am stressed or very tired. I also have a low blood platelet count which a hepatology specialist told me is a complication of HCV. I recently had knee surgery and I had to stay in hospital longer because my low platelet count caused my knee to keep bleeding.
22. I currently have moderate scarring in my liver. I used to have the odd alcoholic drink at Christmas but no longer drink alcohol. The doctor said this has made a positive difference to the condition of my liver. I have not really wanted to ask too much about what the infection does and sometimes think it is best not to know.
23. After my diagnosis, I was told I would get some scans, liver biopsies and other tests. I had been diagnosed for quite some time before I started having liver biopsies and had to have three in total. A needle was stuck in me and the doctor took a piece of my liver for testing. I remember having to lie on my side for hours.
24. For approximately nine years, I was not offered any treatment for my infection. Then from 2005 to 2016 I received three separate treatments.

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25. On 4 March 2005 I commenced my first treatment of pegylated interferon. I had to inject myself weekly with interferon and take a lot of tablets which I believe were ribavirin. The treatment continued for approximately nine months and I had to travel to and from Addenbrooke's Hospital. The treatment did not work and the virus returned after it finished.
26. During this treatment I was barely able to function and felt as if I had no energy and was very tired. I was especially bad on the days after having the injections. I recall going on a holiday to the GRO-B and needing to take my injections across in a cooler bag. I could not do anything all day and had to sit in the car. I only managed to work as by then I was only working a few hours a week.
27. In 2013 I started a six-month treatment of pegylated interferon, telaprevir and ribavirin. It was a mixture of injections and tablets and I experienced dreadful side-effects. In order to deal with these adverse effects, I would take the injection on a Saturday night so that by the time I was due to return to work on the Tuesday I was feeling a bit better. For this treatment I was offered a counsellor who I could telephone and the tablets were delivered to my house along with a special cream. In January 2014 I developed a rash and had a bad reaction to the telaprevir component of the treatment. As a result, I was hospitalised for many days. It was decided I would continue the treatment minus the telaprevir. This treatment was spectacularly unsuccessful. It turned out to be a waste of time and I again felt ill.
28. In 2016 I had my third and final treatment. This time I took tablets and there were no injections. I do not recall the names of the drugs I took but the course went for approximately three months and I did not experience all of the side-effects as I had with the first two treatments. The final treatment worked and for over two years my HCV has been undetectable. I am glad I underwent the third treatment. Now the HCV is gone I feel completely different, but I do worry it might still be there.
29. The mental and physical effects of the treatments I received were terrible. I was aware they had varied success rates, but it was still hard to receive

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letters telling me the HCV was undetectable and then by the end of the treatment it had returned. It is a nasty infection and hides in the corner. I experienced tiredness in general during all the treatments and I had to go on various diets which was awful. During the treatments I could not go on holidays as often as I would have liked and being so unwell stopped my weekly hobby of attending GRO-B It also impacted my ability to play with my grandchildren.

30. The infection did not prevent me from working part time or being able to get out in the garden, except for periods during the treatments. I used to be a GRO-B for a lot of different clients who I gradually stopped replacing and then naturally slowed down until I retired in 2007.
31. When I found out about the infection I was advised by the doctors not to tell people. There was a stigma attached to HCV and I think I was told this to avoid myself and my children from feeling ostracized. I made a concerted effort not to tell others about my infection, including my close friends and extended family.
32. The infection has had a detrimental financial effect on myself and my family. Driving back and forth to Addenbrooke's Hospital is approximately a GRO-B mile round trip and when I was having treatments, I had to travel more frequently. It was a nuisance and the cost of travel is expensive. My husband ran a business and had to take time off work to drive me to the hospital. He was unable to take bookings on those days and this was an additional financial strain.
33. The infection had an impact on those closest to me. When I was diagnosed with HCV the doctors said I did not need to test my children as they were all born before the transfusions but they recommended my husband get tested. My husband decided he did not want to be tested and although we are still married today, GRO-C I found this quite depressing, but it was his choice. We did not stay together for the sake of the children or anything like that but it was difficult.



34. By the time I started my first treatment all my children were adults and the impact on them was minimal as they no longer lived in the family home. During my treatments the main responsibility fell on my husband who had to balance running his business, driving me back and forth to appointments and taking on the cooking and housework duties.

35. Since my diagnosis, I have always been concerned with infecting my children and grandchildren. When I first found out I was infected, one of my daughters was a single parent and I was very involved with my young granddaughter. I remember being concerned about infecting her. I would never go near anyone if I was bleeding. I was told if I injured myself and started to bleed that I needed to ensure no one else touches the blood and to clean the area with bleach. If I was doing anything dangerous, then my family members would need to know there was a risk and they all knew they must inform the ambulance about the risk of infection.

#### **Section 6. Treatment/Care/Support**

36. The only time I recall counselling or psychological support was offered to me was during my second treatment. I probably would have declined support as I would not have wanted to have to travel back and forth for appointments. I don't remember for certain whether I was offered it and I probably would not have wanted it.

#### **Section 7. Financial Assistance**

37. In 2004, a specialist at Addenbrooke's Hospital informed me there was payment scheme available for people with HCV and I might be entitled. I made an application and in 2005 received a £20,000 payment from the Skipton Fund. There were no conditions attached to the payment. I was informed if my condition got worse, such as more serious scarring on my liver, then I could apply for an additional payment and possibly be entitled to more.



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38. From December 2016, I started receiving regular support payments and a heating allowance. In August 2018, I applied for an additional payment based on income and received a top-up. I currently receive £245 per month.

39. I am unsure why myself and others infected with HCV were getting money in this way. It is not really compensation. I think perhaps it was to shut us up. It took a long time from first finding out about my infection to receiving my first payment and then my regular support payments. The Skipton fund should have informed me about its scheme and what I was entitled to earlier.

### Statement of Truth

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

Signed \_\_\_\_\_ GRO-B \_\_\_\_\_

Dated 27 05 2019