

Witness

Name: GRO-B

Statement

No.: WITN5935001

Exhibits:

WITN5935002 -

WITN5935004

Dated: 30-10-2021

INFECTED BLOOD INQUIRY**WRITTEN STATEMENT OF**

GRO-B

GRO-B

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 July 2021.

I, GRO-B will say as follows: -

Section 1. Introduction

1. My name is GRO-B. My date of birth is GRO-B 1952 and my address is known to the Inquiry. I am married with two daughters and three grandchildren. My youngest daughter is expecting twins. My husband and I had our own business for 30 years, selling and repairing electronic and domestic appliances. We sold the business about 15 years ago. I then worked part time in a local school within the finance and administration team. I am now retired and run a small property company.

2. I intend to speak about my infection with Hepatitis C (HCV) contracted from blood transfusions to treat leukaemia in 1988. In particular, I intend to discuss the nature of my illness, how the illness affected me, the

Section 2. How Infected

3. I was born in [GRO-B] My children grew up here. In 1987 I started to feel unwell. During this time, I was busy raising my children, maintaining a home and running a business. When I was running up a hill, I felt dizzy. I went to see my GP who merely told me that I was working too hard and should take some rest. I hadn't needed to see a doctor in years so I knew that something was wrong.
4. I persevered until one day, I collapsed in the park as I was walking the dog. I felt extremely unwell so I took myself home to bed. I woke up in the night to find that I was bleeding very heavily. It was like the worst period one could imagine. My husband was very worried, so I contacted my private gynaecologist. He came over, took one look at me and advised that I should be taken to hospital.
5. I was taken to [GRO-B] Hospital, where they ran some blood tests and I was then diagnosed with leukaemia. However, I had heard on the radio a couple of weeks prior that there was an amazing leukaemia unit at the [GRO-B] hospital in [GRO-B] specialising in treating leukaemia in young adults. I told my gynaecologist that I wished to be treated there. I was taken to the [GRO-B] in [GRO-B] where I was provided with amazing treatment.
6. In 1988, as part of my treatment for leukaemia, I had an autograft bone marrow transplant using my own bone marrow, following on from a year of intensive chemotherapy and blood transfusions. The consultant was lovely. This involved extracting bone marrow from both hips. On the one side, you wouldn't have known anything had happened, but the other hip was black and blue. I was given whole blood and platelets for a couple of years. It took a year to get into remission. After those 2

years, it was discovered that I was anaemic, for which I received further transfusions.

ANONYMOUS

7. In the 90s', there was publicity in the media about Hepatitis C. I was concerned as I had received so many blood transfusions. In 1998, I consulted my GP, Dr GRO-B who has since retired. He ran some blood tests but warned me to be prepared for the answer. I told him that I needed to know. He then invited me in for a consultation where I was diagnosed with HCV. He provided some literature for me to take home and referred me to King's College London which had a good liver unit.

8. I saw a consultant called Christopher Tibbs at King's. He told me that I might get cirrhosis or cancer, but that there was no treatment available and that the best the Hospital could do would be to continue to monitor me. I then had the most terrible liver biopsy. Both I and the registrar ended up crying. It was indescribably painful and traumatic. After this, I vowed that I would never undergo another biopsy.

9. I had also been informed about the risks of transmission by my GP. I was always careful not to share toothbrushes or water bottles with my children. That was something that I have had to live with all these years. My husband was tested, although I don't believe it was suggested that my children get tested too. Fortunately, the results were negative.

10. In 2008, Christopher Tibbs transferred from King's to the Royal Surrey Hospital. I saw him roughly once a year on a few occasions. He informed me that there was a new treatment available, Interferon, albeit its success could not be guaranteed. I went home and researched the treatment, discovering the extensive side effects which effectively amounted to having the flu for a year. I felt as if I knew more about it than he did.

11. I decided against treatment because at this time, I was fit and well. I thought I would wait

and see if treatment improved and hoped my condition would not worsen. He was very keen to initiate the treatment programme, but I felt it was best for the treatment to improve before making a decision. He tried to encourage me but I had already made up my mind.

Section 3. Other Infections

12. To the best of my knowledge, I have not been infected with any viruses except HCV. I was tested for HIV too, fortunately this was negative.

Section 4. Consent

13. I consented to the blood transfusions I was given to treat my leukaemia. However, the risks were never explained to me and as the transfusions were essential in saving my life, there was no other choice.

14. I think I might have been involved in a case study as part of research undertaken by Professor Foster at King's College Hospital. I know that I signed some forms. I was happy to do this and it was all consensual.

Section 5. Impact

15. My diagnosis with HCV came as a terrible blow. The virus was associated with intravenous drug use which made me feel dirty. I was perpetually worried that I could have transmitted the virus to my daughters and to my husband. I took extra precautions to ensure that I would not pass the virus onto them.

16. Whilst I have been extremely lucky as I did not experience physical symptoms from having HCV, I had a constant anxiety hanging over me. I am fortunate to have reached 69 and to be fit and healthy. I am also quite a resilient person but the idea that I might die of liver disease was always on my mind. I was very aware of the possibility of developing cirrhosis or liver cancer.

17. I have had two really terrible liver biopsies. I was really shaken and left bruised and sore. One of the biopsies was inconclusive anyway. I have been told that my liver is very close to my ribs making it difficult to access. I am not sure if that was true or whether the Doctor was trying to justify the pain. The whole ordeal was traumatic and one I knew I could not repeat.
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18. At one time I was bled every week because I had too much iron in my liver. My lovely haematologist at the Royal Marsden informed me that it was dangerous for the liver to have too much iron in the blood. This was prior to receiving treatment and so the doctors were keen to mitigate the damage to my liver in any way they could. They were worried about scarring.
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19. Hospital appointments definitely affected my personal and professional life. I would have to take half a day off work every week to give a unit of blood. When I was diagnosed, my husband and I were running a business. When I should have been there helping my husband, I was going to appointments. I also had to get my mum to look after my children when I was at the hospital. I wasn't there when they got back from school; the whole thing had a knock-on effect.
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20. Having refused treatment with Interferon, I didn't see Dr Tibbs for some time. I have a good friend who works with the BMA and in 2012 I was invited to a talk that was being given by Professor Foster, a leading specialist in viral Hepatitis C, and subsequently I had an initial consultation with him at Barts Hospital on 13 November 2012. He has also provided recommendations to NICE. She introduced me to him and explained my circumstances. He invited me for a consultation at a Hospital in London.
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21. During a consultation in 2013, Professor Foster informed me that a new treatment was soon to be introduced. He told me that as I was fit and well, it would be advisable to defer

treatment. A record of this consultation is exhibited at **WITN5935002**. I continued to see him annually whereby he conducted a number of tests. My liver function tests had not been stable for years, but they didn't appear to be worsening either. He performed a fibro scan as this is non-invasive as I would not undergo another biopsy.

22. I believe the treatment cost between £30K and £40K. NICE would not approve treatment until the price came down. Professor Foster and I waited a long time. I was genotype 1a and the treatment was most suitable for my strand of Hepatitis C. I knew that two and three were much easier to treat. Fortunately, I refused the Interferon because if the virus survives after initial treatment it can become more resistant to a second course.

23. Around 3 years ago, Professor Foster informed me that all the trials had been conducted and that they were ready to treat healthy people. I was told that I had a 90 percent chance of clearing the virus and that the side effects would not be terrible. I was given Zepatier, a combination of two different medicines in one pill. I took 2 tablets once a day for 13 weeks. Fortunately, the treatment was successful and I was cleared of Hepatitis C.

24. I did not experience flu like symptoms as Dr Tibbs warned with Interferon. However, I didn't sleep well. I was constantly thirsty and often had a slight headache. The hospital had a very good specialist nurse who checked me every week. Nine times out of ten I would see Professor Foster which was very impressive, considering he was a top consultant. I thought he was amazing. When I met him, I knew I had met the right person to help me defeat this virus.

25. After clearing the virus, I continued to see Professor Foster annually. Since the pandemic, this changed to telephone conversations. On one occasion, I missed the call with the

Professor so he requested that my GP run liver tests. He assured me that he wouldn't let me go until he is absolutely sure that I am ok and he stuck to his word. My liver has been permanently affected; there is absolutely no doubt of that. I was told that my liver was scarred and is a level 'eight'. He said it should be below ten.

26. From my experience, there was definitely a stigma associated with a Hepatitis C infection. When I had my ovary removed, I had to be the last person in the operating theatre. They also had to deep clean the theatre after the operation. I found this very embarrassing. I always felt the compulsion to divulge to medical professionals that I had been given this illness from contaminated blood, as I was acutely aware of the connotation of the virus with drug use, which was quite humiliating.

27. If I attended the dentist, I had to declare my HCV status. Dentists more than doctors changed their attitudes towards me. They would be double masked and double gloved. I was required to fill out a form outlining that I had the virus and felt I needed to justify how I contracted it, which was also uncomfortable. It is a big relief that I don't have the virus any longer.

28. Since my diagnosis with HCV, insurance has been a problem. I have always had to pay more than the usual to be covered. I have not even tried to apply for life insurance as I don't think anyone would insure me. This worries me.

29. My diagnosis was difficult for my husband to reconcile. He was left with the uncertainty as to whether I would be around in the future. Our sex life was also affected. I had to be very careful as I was aware that it could be passed on during intercourse.

30. Otherwise, I only told close friends. One of my friends couldn't fathom how I could go on

with a 'killer disease'. I told her that I didn't have much choice. I wouldn't have survived leukaemia without the transfusions and so it was a trade-off. I wanted to have enough years to see my children grow up. At one time I was having platelets and blood every day, for weeks and weeks. I guess it was inevitable.

31. At the time of my diagnosis, my daughters were too young to understand my illness and the circumstances surrounding my illness. However, I told them about my HCV infection when they were old enough. They were very concerned, particularly in their early teenage years.
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Section 6. Treatment/Care/Support

32. I was only tested for Hepatitis C after seeing publicity about the virus in the media. I knew that I had received an abundance of blood and blood products over many years. However, I wouldn't have known that I was infected, unless I had been proactive and followed up what I saw in the news. Up until then, I was healthy and it had never occurred to me that I might have an illness.
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33. During my appointment with Christopher Tibbs, I felt that I was provided with sufficient information about the illness. However, it was difficult to be told that there were no treatments available. It felt like I had this killer virus hanging over me and there was nothing that I could do to help myself.
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34. Dr Tibbs said to me that I knew more about the virus than he did. This didn't instil the greatest level of trust in his expertise. Conversely, I always felt very looked after by Professor Foster. He was readily available and always provided a breadth of information and support. Nevertheless, the expertise of Professor Foster was only available to me through my own contacts.
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35. If I didn't have a friend who knew of Professor Foster and had been proactive in sourcing

treatment, I wonder where I would be now. He knew the best treatments and was fantastic. However, I think I was lucky. I don't think normal liver specialists like Dr Tibbs had the requisite knowledge in treating something like Hepatitis C.

36. I have never been offered psychological support or counselling since my diagnosis. I think it should have been offered. For some people this would have been essential.
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Section 7. Financial Assistance

37. In 2003, I read in the press that the government had decided to recompense those who had contracted Hepatitis C at the hands of the government. I contacted the Department of Health to enquire. A copy of this letter is exhibited at **WITN5935003**.
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38. The Department of Health contacted me later that year, as exhibited at **WITN5935004**. They had decided that sufferers should in principle receive ex gratia payments which would be overseen by the Skipton Fund. However, they were still considering the details of the scheme and were to contact me in due course. It was all very vague and I wasn't sure if it would go further or not.
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39. In 2014, Skipton sent me some paperwork. Initially, I wasn't sure if I was eligible as apart from liver scarring, I wasn't physically affected by the virus. I phoned the fund and spoke to a very nice lady who assured me that my circumstances were definitely applicable. She also assured me that whilst I wasn't a textbook case, I was likely to be successful.
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40. She assisted me with the process by explaining which sections to fill in. She was very helpful and advised that I provide supporting evidence from my haematologist at the GRO-B Hospital. I included a cover letter from both my GP at GRO-B Surgery in GRO-B and Dr Jennifer Treleven

at the Royal Marsden.

ANONYMOUS

41. My application was successful. I didn't receive a response instantly but nor did I wait long either. I received my first payment of £20,000 in November 2016. I also received an annual payment of £3,000, plus a £500 winter fuel allowance as of 1 April 2016. The monthly payments have since increased.
42. It's difficult to say if the payment I received was a reasonable amount. I have probably had Hepatitis C since the 1980s. I received financial assistance many decades after this. If you take the amount I received and divide it between the years, it is not much.
43. Skipton were very efficient and supportive. I have absolutely no complaints. However, whilst I am grateful that people like myself are being recompensed, this has been going on for such a long time. I feel that the government delayed initiating financial support so that there would be fewer people left to compensate.

Statement of Truth

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

Signed

GRO-B

Dated

30-10-2021