

ANONYMOUS

Witness Name:

GRO-B

Statement No: WITN4176001

Exhibits: WITN4176002-3

Dated: May 2020

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 GRO-B and I live at GRO-B
GRO-B

2. I am infected with the Hepatitis C Virus (HCV) through contaminated blood products and/or transfusions.

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

Section 2. How Affected

4. I have had various blood products, platelets and transfusions to include Intravenous Immunoglobulin (IVIG) transfusions from the 1980s at the Royal

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Liverpool Hospital (RLH) and Aintree University Hospital (AUH), formerly known as Fazakerley Hospital.

5. In 1984 when I was GRO-B years old I was identified as having severe Idiopathic Thrombocytopenia Purpura (ITP) an autoimmune disease (incidentally diagnosed by identifying my low platelet count). I was given the first of many IVIG treatments. I did not know in 1984 when I first had IVIG that it was a blood product. I assumed it was a drug product to raise my platelets. I don't think I realised that it was a blood product until more recently (in the last ten years or even less).
6. I had various transfusions when I gave birth to my children. My eldest son was born on GRO-B 1989. I was still not aware back then that IVIG was a blood product.
7. In June 1990 I had 10 units of platelets during the excision of my wisdom teeth at RLH and platelets and IVIG treatment at AUH when I had viral meningitis in 1991.
8. From around the early 1990s I became very unwell and developed chronic fatigue. I had a low immune system and picked up a lot of opportunistic infections but no-one could work out why I was so exhausted all the time as my blood count was under control. I now suffer with a multitude of serious health issues that I have developed since around the time of the birth of my three children born in 1989, 1994 and 1996. By 2008 I had developed aplastic anaemia and, later, needed treatment of myelodysplasia.
9. In 2012 I saw a dermatologist (I do not recall her name) and she told me that I was infected with HCV. Because of my skin symptoms I agreed to her doing a number of tests to include hepatitis but I thought little more of it after she took my blood. It was the first time I was *knowingly* tested for infection. The dermatologist then phoned me and asked me to come in to see her. At a meeting outside of her ordinary clinic appointments, she informed me that I

had HCV antibodies. I had the distinct feeling of being taken to one side to be told as there was no-one else around. She told me that I had 'probably been infected from a blood transfusion'. The subsequent PCR test came back that the HCV was either at low levels or had cleared. The probability that I was infected from a contaminated transfusion has since been confirmed by my GP and the clinicians at GRO-B where I had a stem cell transplant in 2014.

10. I refer to **Exhibit WITN4176002** being one of the very few relevant medical documents in my possession. Despite only being told in 2012 that I had been exposed to HCV, I was clearly identified as having HCV from a blood sample collected for testing on 20th January 2010. It was confirmed as 'anti-HCV detected due either to recovered (non-viraemic) infection OR chronic infection with a poor immune response'.
11. During the stem cell transplant in 2014 I had what I believe to be a full on HCV flare up/eruption with yellow eyes, skin and other problems – possibly/probably due to immune suppression allowing the viral load to increase. My haemato oncologist suggested that HCV would emerge during the transplant.
12. Because I have low immunity, my body may not be able to completely clear the virus and/or may be providing a false negative test result. I am in some doubt as to whether I have cleared the virus or not and I believe I am in need of a more sensitive test that will provide a definitive answer as to whether or not I am still infected. Because of my state of ill health I believe that I am still infected with HCV.
13. I have been trying to obtain my medical notes from the RLH for a significant period of time. I was at first informed that they had been destroyed. I subsequently took a phone call informing me that they were not destroyed and they would carry on looking for them. It has been a battle to obtain them and I have chased the RLH again recently.

Section 3. Other Infections

14. Referring again to **Exhibit WITN4176002**, I was tested positive for the Epstein-Barr Virus (EBV) in 2010. I refer to **Exhibit WITN4176003** being a letter from the **GRO-B** to my GP dated 4th September 1991 advising that I might have had Acute Disseminated Encephalomyelitis secondary to the Hepatitis B vaccine.

Section 4. Consent

15. I did not provide consent to an HCV test before 2012 and I refer once again to the fact that I was tested for hepatitis (HBV and HCV) prior to that date.

Section 5. Impact of the Infection

16. I suffer with a variety of serious health issues to include low immunity and frequent infections; bronchiectasis; bowel and gastrointestinal tract problems (with severe abdominal pain and pain from my liver region) and a choledochal cyst; fibromyalgia; pain and weakness in my hands, wrists and thumbs; severe hearing loss; dry eyes; wide spread joint tendon and muscle damage and pain; foggy cognition with forgetfulness and confusion; chronic fatigue; insomnia; osteoporosis and low mood. I have had myelodysplasia resulting in bone marrow treatment. I would have probably died without the treatment.

17. The chronic fatigue that I have endured since the 1990s has been all encompassing. I was never able to fully enjoy the experience of being a mother to my young children. I spent days at a time in bed. I would try to rest whilst the children were at school so that I could give them some of my attention when they came home. I had no energy and no interest in anything. Being infected with HCV and my poor health has affected my relationship with my children and with friends. It destroyed my marriage. My husband left in 2013.

18. I was retired in 2007 on the grounds of ill health after a fight with GRO-B who were just going to sack me (dismiss me). I was literally falling asleep at work. I had worked for GRO-B from 1994 through to 2007 with time off sick from 2001 when I still had my part-time job at GRO-B but secured a position as a part-time radiographer. By July 2001 my children were all in school and I decided to try to get back into radiography. It was not something I could consider before the children were in school because my husband worked shifts and I couldn't also work shifts. On the day I was returning to radiography I was taken into hospital with a bone marrow crash and my aplastic anaemia was later diagnosed.

19. I have not been able to work since 2007 and the financial impact that has had on me has been huge. I have tried to work but the fatigue, joint pain and memory problems have made that impossible for me. I am mainly reliant upon welfare benefits (with a small pension from the GRO-B of around £200 per month) and I have had to fight tooth and nail to keep them. Because my health issues are not visible, it is exhausting to have to convince others that I am unwell. I gave serious consideration to becoming a counsellor. I wanted to help others like me and counselling was something I could have done on a part time basis at my own pace when I was up to it. I went to University and managed to complete a year before having to give up last year four weeks into my second year because I was too ill.

20. I believe many of my health issues to stem from the HCV infection, particularly as my liver is almost always sore. I can never get a straight answer as to the source of all my problems to include the fatigue, memory loss and aching muscles from my clinicians. Nothing has ever been explained properly. All my notes and files have 'Biohazard/high risk/warning Hepatitis C' labels or have mention of it. There is never a day that goes by that I don't worry about my health. I worry the HCV infection will flare up and that I will go back to square one. I worry constantly that I will end up with full blown liver cancer or something like that.

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21. I worry about my children every day. I had HCV for so long without knowing about it that I might have passed it on to them. I have been in turmoil worrying about it.

GRO-B

Section 6. Treatment/care/support

22. My GP is supportive but there is little she can do as there isn't a definitive or sensitive enough test I can have. If there were, I would fear the result.

Section 7. Financial Assistance

23. I have not had any assistance from the trusts and funds. My application to the Skipton Fund was refused because I was unable to pinpoint when I was infected with HCV. I was put off from applying fully in a phone call with a man in the Skipton Fund. Because I was so ill at the time I didn't have the energy to look into it further.

24. With the full help and support of my GP I have recently re-applied (to EIBSS) for financial assistance and I am awaiting what I believe will be a positive response.

Anonymity

25. I am seeking anonymity.

Statement of Truth

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

Signed.....

GRO-B

Dated

20.05.2020