

ANONYMOUS

Witness Name

GRO-B

Statement No: WITN3011001

Exhibits: WITN3011002

Dated: 1st July 2019

INFECTED BLOOD INQUIRY

EXHIBIT WITN3011002

ANONYMOUS

Witness Name: GRO-B: H

Statement No: WITN3010001

Exhibits: 0

Dated: 9th April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GRO-B: H

I, H will say as follows:-

Section 1. Introduction

1. My name is H and I live at GRO-B
GRO-B I was born on GRO-B I am married to GRO-B
GRO-B, and have been since GRO-B, we have been together since
GRO-B. We have GRO-B children; our GRO-B and our GRO-B I do
not work now but I was a self employed GRO-B
2. This witness statement has been prepared without the benefit of access to my
medical records.
3. I am aware that GRO-B, also intends to provide a statement to the Inquiry.

Section 2. How infected

ANONYMOUS

4. I have mild Haemophilia A and was diagnosed in GRO-B when I was around 2 years old, after a bleed in my mouth. I was taken to my GP, then the hospital, before being treated in GRO-B. I was living in GRO-B at the time.
5. In GRO-B, when I was GRO-B years old, I was transferred to GRO-B under the care of GRO-B. When he retired the consultant that took over was GRO-B.
6. I was originally treated with cryoprecipitate before being treated with (Fhandi) Factor VIII concentrate. It was a powder which had to be reconstituted with water before being injected it into my vein.
7. For the most part I would attend GRO-B and have injections, but I also had injections at home.
8. At the age of GRO-B, I developed an antibody to Factor VIII which, at the time, was awful. I had to be treated with Autoplex instead, which was a man made Factor VIII, and I was treated with it until GRO-B when I underwent a GRO-B operation. Prior to this operation, the hospital managed to get rid of the antibody present in my body through chemotherapy as a result I started taking Factor VIII again.
9. I have received blood products since the age of 2 years old; however I was never provided any information or advice beforehand about the risk of being exposed to infection as a result of receiving blood products. It was a given that I needed Factor VIII so I just accepted it.
10. As a result of receiving blood products, I was infected with Hepatitis C (HCV).
11. I was told of the infection in GRO-B when I was GRO-B years old. I went to an appointment at the GRO-B on my own as I was feeling unwell.

GRO-B, the clinical nurse specialist, told me that I had HCV. I felt they already knew I had HCV.

12. I was then given a fibro scan to my liver. At that stage the liver damage was not extensive and they talked to me about the available treatments. I was told about a combined treatment, but they said that there was only a 70% success rate, I accepted the advice and I decided to wait.

13. I accepted what I was told at the appointment and I did not think too much of it. If I had been given more information at the time I would probably have made more of an informed decision.

14. **GRO-B** was the gastroenterologist who looked after me throughout my HCV treatment.

Section 3. Other Infections

15. As far as I am aware, I do not have any other infections as a result of receiving blood products.

Section 4. Consent

16. I am not aware that I was tested or treated without my knowledge, but I would hope that I was not. However, I was never told that I was to be or I had been tested for HCV.

17. My body has a natural immunity to Hepatitis A and Hepatitis B so **GRO-B** **GRO-B** would often take extra blood samples from me to use in their laboratories for research.

Section 5. Impact of the Infection

18. In [GRO-B], soon after I was told that I had been infected with HCV, I was shocked, but I accepted what I was told; it explained the reason I was feeling so unwell and tired all the time, but I was pragmatic.
19. HCV caused me to have further medical complications. Following my diagnosis with HCV I had fibro scans every six months and at the end of [GRO-B] told me I had cirrhosis of the liver. I never received any treatment for this condition.
20. I also believe that intra abdominal varices caused a variceal haemorrhage in my abdomen, resulting in a severe bleed. This first happened in [GRO-B] and the hospital managed to stop it with Factor VIII. However, it happened again and so they ended up inserting coils in to repair my splenic artery. This was called a splenic artery aneurysm embolisation.
21. In [GRO-B], I was also diagnosed with terminal metastatic colon cancer. I believe that at the very least, the treatment I received for HCV compromised my immune system and what it did to my body, caused or exaggerated the cancer.
22. My treatment for cancer was a combination of chemotherapy (Folfiri) and also Cetuximab, which was infused into my body via a drip. I had chemotherapy for 6 months fortnightly and then they continued with the infused treatment for the remainder of the 14 months at [GRO-B]. Following a scan I was told that treatment was not working anymore.
23. I was then given folfox, which was second line chemotherapy, at [GRO-B] [GRO-B]. After 3 months I was scanned and it showed it had stopped working and the tumours had grown and so they stopped the treatment. We discussed third line chemotherapy (Lonsurf) but I only had one dose.

24. In **GRO-B** my pain increased and after a scan there was no change it was decided to stop all treatment and I was told that there is nothing more that they can do. It was then that I was referred to the hospice. Just after we were told this, my pain worsened and I was admitted to a hospice for pain management before I was able to come home. My condition has worsened since and I am now bedridden.
25. In **GRO-B** I began treatment for HCV. I started the bisesrophere course which was a combination of PEGylated Interferon and Ribavirin. I was on this treatment for a year, 48 weeks.
26. I had a check up after 24 weeks and the tests showed that the treatment was working and that I was responding to it. I therefore continued for the full course, however the treatment was unsuccessful.
27. In **GRO-B** I was then given Harvoni treatment (Sofosbuvir and Ledipasvir). I was given Harvoni and Ribavirin together. I received this for around 3 months and I finished the full course. In **GRO-B** I was told HCV I was clear of HCV.
28. I faced no obstacles in obtaining treatment. There is nothing that I am aware of, that I feel that I should have received. I felt that I was always fully informed of whatever was available and that I had access to everything available.
29. The effects of my treatment in **GRO-B** where both physical and mental. I accepted what was happening and I took on anything they were going to throw at me to sort it out, in terms of treatments. The first treatment (bisesrophere) got me down after finding out it did not work after being so unwell throughout the treatment course; I was so disappointed that it did not work in the end.

30. Physically, I became very anaemic and I found the treatment very debilitating.

The first treatment was worse than the second one. I had to have a year off work and as I was self employed, I had to close my business for a year.

31. The second treatment (Harvoni) was not so bad and I managed to continue working through it as by this time I was doing less work and I was employed

GRO-B

My employer let me have time off when I needed it for treatment and hospital appointments.

32. My dentist refused to treat me due to my HCV infection and so I had to attend GRO-B

GRO-B

for any dental work. My dentist treated me prior to this when only my Haemophilia condition was known about.

33. I always kept information of my infection very quiet; I only told my best friend. At

the time of my diagnosis our children were too young to know GRO-B

respectively GRO-B and I told the children when I started my treatment in GRO-B

they were GRO-B Our children already knew that I was poorly most of the

time and so when they became older we told them, they were very accepting. If I was poorly it was due to the Haemophilia, it was easier to justify.

34. Both GRO-B and I felt unable to tell people and uncomfortable speaking about it, purely due to the stigma attached to it. If you had HCV you were known as a 'druggie', that was the assumption and no one really knew otherwise; we did not even tell our parents.

35. I was working when I was first diagnosed and I continued to do so, it was my choice to delay the original treatment offered. I was feeling poorly but still continued to go to work, whilst perhaps doing fewer hours than I would have otherwise have done.

36. When I had the first treatment I stopped working for a year. I then returned to work as a GRO-B. In GRO-B I stopped working when I was diagnosed with cancer.

37. Financially, my infection impacted on my ability to work. We only managed to survive because my wife worked full-time. During that decade I could not grow my business as I would have liked to have done.

38. Life and travel insurance were very expensive and hard to obtain for me which was a further complication and worry. I had life cover attached to our endowment mortgage, when it matured the cover stopped and at that stage it was impossible to get further cover due to my illness.

Section 6. Treatment/care/support

39. I believe that GRO-B and I were offered counselling, but we are not the type of people who that it would work for, so we declined the offer.

40. We received no other offer of care or support.

Section 7. Financial Assistance

41. I found out about the Skipton Fund through the Haemophilia Society, and also GRO-B told me to apply.

42. I contacted the Skipton Fund and on GRO-B I was registered and they sent all the paperwork they wanted me to complete for the first application. GRO-B completed their part of the form and returned it to the Skipton Fund. I received the Stage 1 lump sum payment of £20,000 on GRO-B.

43. When I was told that I had cirrhosis of the liver in around GRO-B, I applied for the Stage 2 payment. I was told in GRO-B I believe and then on GRO-B I

received the Stage 2 lump sum payment of £50,000. The amount had recently been increased from £25,000.

44. We also get Stage 2 monthly payments as on GRO-B It is currently £18,432 per annum.

45. The Skipton Fund was very well run in my experience.

Section 8. Other Issues

46. I have no other issues.

Section 9. Anonymity, disclosure and redaction

47. I confirm that I wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

48. I do not wish to be called to give oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

H

Dated: 9th April 2019