

Witness Name: Simon John Hall

Statement No: WITN4004001

Exhibits: WITN4004002

Dated: March 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SIMON JOHN HALL

I, Simon John Hall will say as follows:-

Section 1. Introduction

1. My name is Simon John Hall. I was born on the GRO-C 1955. I live at GRO-C
GRO-C I haven't worked for five years because I am disabled due to chronic fatigue syndrome, Chronic Obstructive Pulmonary Disease (COPD) and Irritable Bowel Syndrome (IBS). Two separate consultants have said that my conditions are so severe as a result of having Hepatitis C for some 40 years.
2. I was a Senior Project Manager. I built five star hotels in the Middle East. I was also a client's representative for the Royal family of Bahrain.
3. I now live with my partner who is also my carer.
4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records, the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Infected

5. In 1976 I walked into the A&E department at Cheltenham General Hospital because my appendix was swollen and then it burst. I told them what had happened and they didn't believe me and said that I would not been able to walk into A&E had my appendix actually burst. They left me sitting in the room for hours. Approximately eight hours later, one surgeon had a look at me and realised the severity of my situation and then I was rushed in surgery. I was operated on, and during surgery, I received a blood transfusion.
6. I requested my medical records and I have been told that there are no records of me having a blood transfusion in 1976. There are no records of the doctors or theatre assistance that were involved in my operation and transfusion. I do not have any medical records from 1976 to 1984.
7. I was not given any information about the risk of infection before I received the transfusion.
8. I was first diagnosed with Hep C in 1980. I was often very ill, after the blood transfusion and my immune system was very low. I therefore went to see my GP, who took some blood tests. The blood results showed that I had abnormal liver function (LFT). The doctor asked about my lifestyle, for example drinking alcohol and said that I would have to stop drinking.
9. My GP specifically used the word 'Hepatitis C' when I was told about the LFT in 1980. That was the first and only time he made reference to 'Hepatitis C' after that the other doctors referred to Hep C as an 'abnormal LFT'. I had never heard of Non A, Non B Hepatitis.
10. I was given no information about the infection, even the doctor didn't know. It was a new infection at the time and there was not much information surrounding it at all.
11. I was not given adequate information about the infection and the risks that it posed to me.

12. The information that was given to me about Hep C definitely should have been provided earlier.
13. The results of the tests weren't really communicated to me at the time, mainly because the doctors didn't even know anything about the infection as it was a new disease. They didn't check up on me or invite me back for further tests until I became ill in the mid 1990's. It was only when I got ill again they checked my liver again.
14. I was not given any information about the potential risks of infecting others.
15. My Hepatology team believe it was a blood transfusion that I had in 1976 but we have no evidence of that.

Section 3. Other Infections

16. I do not believe I received any other infections as a result of the blood transfusion.
17. I had repeated strange illnesses from 1980 up until 2016 but the doctors couldn't figure out what it was. It wasn't until 2016 the doctors told me that it was liver related which had been caused by my Hep C.

Section 4. Consent

18. I was most certainly treated with infected blood products without my consent. I also believe I was tested without being given adequate information.
19. I do not believe that I was tested for the purposes of research.

Section 5. Impact of the Infection

20. At the time when I found out that I had Hep C, I didn't really know what it was and therefore didn't really know how to react. No information was given at the time about the information.

21. However, as the years have gone by, the infection has affected me badly. I have had long mystery illnesses which the doctors have never been able to work out.
22. I have had dreadful fatigue, loss of appetite and weight loss. I now have IBS, chronic fatigue and fibromyalgia. My muscles and joints are screaming in pain as a result and I have to take strong painkillers all the time. I sleep for 14 hours a day, sometimes 24 hours a day when I have a flare up. On top of this, I also suffer from brain fog and I have developed a stutter.
23. I believe all of the above symptoms are as a result of the Hep C infection and the doctors and neurologist confirm this as well. I do not believe it can be anything else. I don't drink and I gave up smoking nine years ago. I have a Mediterranean diet.
24. I also suffer from lichen planus in my mouth, which I believe is as a result of the Hep C. It makes it particularly hard to eat hot or spicy foods and causes problems with eating altogether. This symptom started about four years ago. It's not like mouth ulcers, but, instead, they appear as white painful lines all the way through your mouth.
25. In 2018 I was given my first set of treatment of Epclusa for Hep C. I was told that they couldn't treat me with Interferon because I was so ill and it would have killed me. The Epclusa treatment was a 12 week course and it cleared the infection.
26. I had one blood test for Hep C every three months in the first year and now I have one blood test every six months. The last blood test that I had showed that I am still clear of the infection.
27. I don't believe I faced any obstacles in getting the above treatment at the time, although I feel like I have been ignored for many years. Haemochromatosis is what the Hepatologist thought that I had. But they have no explanation as to why my liver function tests were so high and they said that they expected my liver to be bleeding, but it was not.

28. There were treatments out there that I believe that could have been available for me, but as stated above I feel that I was ignored. Dr Hellier, a consultant, said that I was very badly let down by the NHS.
29. The infection just kept making me ill. I was in a stressful job and I believe that could have been one of the reasons why the infection would flare up. I was always falling ill and taking time off work.
30. I didn't really get stigmatised, because no one really knew what it was at the time. In the 1990s it had more of a stigma, but I would always tell people, such as the dentists and most people were good about it.
31. The infection did affect my work. In the 1980s I would occasionally be off from work on sick leave for a matter of months. However, my symptoms got worse and therefore I stopped working between 2001 – 2005. I did return to work, however, I medically retired in 2015.
32. When I was working I took so many sick days. But I couldn't tell my employer at the time, due to the nature of the work that I was carrying out.
33. It has had a phenomenal financial effect on me as I had to quit my job. I would have continued working past my retirement age.
34. My family have been very supportive of me about my infection.

Section 6. Treatment/care/support

35. I do not believe that I had any obstacles in obtaining treatment, care and support. However, as stated above I feel that I have been ignored until my infection kept flaring up and they said that they should have seen me earlier.
36. Psychological support was not given to me. It would have been better and I would have had a better understanding if things were explained in more detail to me.

Section 7. Financial Assistance

37. I have not received any financial assistance. I completed all the necessary forms for the Skipton fund and as instructed by the Skipton Fund they were passed onto the Haematology team who were responsible for my care for signature. The consultant did not sign them and left them sitting on his desk for nearly two years.
38. I was told by the Hepatology team to apply for the Skipton Fund. I wasn't initially refused the funds, but no one got back to me when they became part of the EIBSS, as the consultant had not sent the necessary forms to them.
39. I have contacted the EIBSS and they have refused any help. There is apparently no record of me having a blood transfusion. There is no proof of me not having the blood transfusion and they are using the fact I have no records erroneously.
40. The EIBSS accused me of being a drug addict, Exhibit WITN4004002. They had no evidence of this so I sent them a letter saying that I was going to take them to Court for defamation of character. They did call me to apologise after this, and wrote a letter of apology, but in the circumstances this is completely worthless to me.
41. The funds that are available are disgusting, they are worthless. The administrators just sit there to stop people claiming and to protect certain people in politics. It's all underhand, which is putting it lightly.
42. The last letter I received from the EIBSS states that I could appeal their decision in a court in London. I cannot appeal it in person however, as they do not take oral evidence. This means that it is a kangaroo court, if I cannot give evidence the decision is made before I even apply. I honestly don't believe the Skipton Fund or the EIBSS have done a lot because they responded to me too quickly.

Anonymity, disclosure and redaction

43. I do not wish to remain anonymous.

44. I am open to giving oral evidence, depending on my symptoms at the time.

Statement of Truth

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

Signed...

GRO-C

Dated

30-3-2020