

Witness Name: Simon Christopher Brown

Statement No: WITN1110001

Exhibits: 0

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SIMON CHRISTOPHER BROWN

I, Simon Christopher Brown will say as follows: -

Section 1. Introduction

1. My name is Simon Christopher Brown and I was born on 1962. I live at Cardiff,
2. This witness statement has been prepared with benefit of access to some of my medical records.

Section 2. How infected

3. My mother was a known Haemophilia carrier, so prior to my birth it was suspected that I may be born with the condition. As such, I was tested at birth and I was diagnosed with mild Haemophilia A with around 15 – 18% clotting factor.
4. I initially received Cryoprecipitate for any serious bumps or cuts. I was later treated with Factor VIII, but I cannot recall when. I had a limited number of hospital visits as I only required treatment for injuries, which did not occur very often. I only received treatment for significant intra-muscular injuries or

bruising that could not be controlled through immobilisation. I have also required treatment during surgical procedures.

5. The earliest record I have for a medical procedure was when I had hernia repair in August 1990. However, I believe I was treated with Factor VIII earlier than this when I was around 21 years old, in or around 1983, as I had my wisdom teeth extracted at Hillingdon Hospital. It is also likely that I received Factor VIII for an ingrown toenail when I was 13 years old, in or around 1975. I cannot state the exact time period I received the Factor VIII and was infected
6. Since approximately 1986, I have been under the care of the University Hospital of Wales, Cardiff. Prior to this, I was treated wherever my parents were stationed in the military, or where I was at school/university.
7. Sometime in or around 2000, I was contacted by the University Hospital of Wales. I received a letter which advised me that I may have become infected from blood products and that I should make arrangements to be tested. My grandfather was being treated at the Oxford Haemophilia Centre at the time, so he arranged for my brother and I to undergo blood tests there. I received the results through the post and I was advised that I had not been infected with HIV, but I had tested positive for Hepatitis C (HCV). Fortunately, my brother was not infected.
8. I was later seen by my doctor at the University Hospital of Wales. He informed me that I had been infected with the Hepatitis C Virus as a result of contaminated blood. He also gave me verbal advice about precautions that would be required to reduce the risks of others being infected as a result of my infection, but nothing further in relation to treatment was discussed.
9. I believe there is a possibility that my liver was being monitored prior to 2000. I remember attending the hospital for routine check ups during which I had to give blood. I did not think much of this at the time, but now I believe that I was being tested for infections.

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11. The University Hospital of Wales provided very little ongoing advice. Fortunately, I was able to research the infection and gained an understanding of how little the profession actually understood about the problem. I also became aware that there was no viable treatment available at the time and the conversion from infection to full cirrhosis could not be predicted.

Section 3. Other Infections

12. In addition to my tests for HIV and HCV, I have also been tested for CJD.

Section 4. Consent

13. Please refer to paragraph 7 to answer the questions under this section.

Section 5. Impact of the Infection

14. Being infected with Hepatitis C has overshadowed a large part of my life. I was forced to conduct my affairs in a covert manner, keeping my potential condition a secret while I received medical testing. During this time period, people with HIV were being shunned and assaulted for being 'gay' in the UK.

15. I subsequently had to

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In addition to this, coming to terms with a virus that could progress to full liver failure with no known cure (at the time), was a key factor in us deciding not to have a family together.

16. I felt forced to not disclose my medical condition to my colleagues and close friends for fear of losing my job and failing to secure a new job or failing to progress with my career. There was also the stigma attached to HIV and

Hepatitis C which made it more difficult to tell my colleagues and close friends.

17. I was treated with a combination treatment of Ribavirin and Interferon, lasting 26 weeks, which began on in October 2006. During the treatment, I suffered psychological issues and I asked the hospital for psychological support, but this was not provided to me. For this reason, and the irrational arguments generated by me with my wife, I went to live with my parents in a secluded cottage in North Wales. I also banned myself from driving due to the potential lack of control over my emotions that I was experiencing.
18. The treatment itself was successful but left me severely weakened. I was extremely tired, I had severe headaches that affected my mood, I was constantly vomiting and suffered with bowel problems each day, I also ended up losing some of my hair which I have not recovered since. As a result of the side effects, I became house bound and isolated as I did not feel like socialising with anyone. It was a long painful road of recovery to normal fitness.
19. To undertake such a demanding six-month treatment with significant side effects resulted in me being selected for redundancy during a company restructuring process. I firmly believe this distressing process would not have happened if I was healthy and 'in work' at the time of the restructure, however I had to take a lot of time off due to feeling unwell. The treatment left me too weak to argue.
20. During the treatment, I was particularly stressed by the fact that a failure to positively respond to the treatment by week 16 would result in termination of therapy with no prospect for alternative treatment. Fortunately, the test at week 16 demonstrated a positive response to treatment which was a big relief.
21. Although I still undergo monitoring every six months, I have remained virus-free and I have now been able to find another job. However, I spent 12 weeks trying to find alternative employment. This proved very difficult because I was

not able to disclose my medical condition until enough time had passed to be able to say I was fully recovered. In the end, I was able to secure an alternative job at the factory that had made me redundant. The financial effects were limited by my ability to negotiate a similar salary. This was only possible because I applied for a job role that required specialist engineering knowledge that could not be supplied by other candidates at the time, despite the company advertising and interviewing nationally.

Section 6. Treatment/care/support

22. I asked the hospital for psychological support, but this was not provided to me. It would have helped if I had professional support available to me due to the fact that I was going through such a difficult time.

23. I did not face any difficulties obtaining the treatment for my Hepatitis C virus once it was available to me in October 2006.

Section 7. Financial Assistance

24. I received an initial Stage 1 Payment of £20,000 from the Skipton Fund, however I cannot recall when. In order to receive this payment, I had to contact the Fund and they sent me a form to fill in. I cannot remember if I had to provide them with medical information or if the hospital provided them with it.

25. As far as I can recall, the application process was fairly straight forward, and I did not have any difficulties.

26. I also receive a monthly payment from the Wales Infected Blood Support Scheme (WIBSS).

Anonymity, disclosure and redaction

27. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

28. I am happy to provide oral evidence to the Inquiry.

Statement of Truth

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

Signed.....

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Dated.....

4/4/2019.