

Witness Name: Steven John Towsey

Statement No: WITN1570001

Exhibits: 0

Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEVEN JOHN TOWSEY

I, Steven John Towsey, will say as follows:-

Section 1. Introduction

1. My name is Steven John Towsey. My date of birth is GRO-C 1972. I am married and live with my wife at GRO-C
GRO-C. I have 6 children all of whom have left home.
2. I was infected with hepatitis C as a result of being treated with Factor VIII (FVIII) blood products. I am no longer infected with hepatitis C, although the antibodies remain present.
3. This witness statement has been prepared without the benefit of access to my full medical records.

Section 2. How infected

Family history

4. In 1978, doctors diagnosed me with mild Haemophilia A. I do not suffer from any other bleeding disorders.

5. [GRO-C] I am the eldest of 6 children; I have 4 brothers [GRO-C] and 1 sister. I used to have 5 brothers but, in 2010, one of my brothers, Graham, died as a result of being treated with contaminated blood products. He was 32 years old when he passed away.
6. My mother was also a carrier and she died a few years ago but her death was unrelated.

Lewisham hospital, London (LH) 1978 to 2000

7. From 1978 my parents took me to Lewisham hospital (LH), South London to be treated. My bleeds were usually caused by trauma but were sometimes spontaneous. They took me to LH on average 4 or 5 times per year for treatment and doctors continued to treat me until I was old enough to treat myself at home.
8. My medical notes reveal that in 1984 doctors were using Cryoprecipitate not only to control my bleeds but also as a cover for hepatitis B vaccine.
9. Dr [GRO-D] was initially the main haemophiliac consultant at LH. I believe this consultant was replaced by Doctor [GRO-D], another consultant haematologist.

Factor VIII Products

10. Between 22 October 1979 and 29 October 1979, doctors at LH used FVIII products to stop my bleeds for an injury to my left hip. It is possible that they treated me with these products before then, but I cannot say for certain.
11. The doctors never advised my parents about any risks of being treated with FVIII products and they continued to treat me with these products throughout the 1980's.

12. It was not until the late 1980's there was a growing concern amongst parents that hospitals were using blood products that were unsafe. Despite these concerns, doctors failed to advise my parents of any risks and continued to use them. My mother, at some stage, became so concerned that she decided against taking me to LH and would only do so if my bleeds were severe.

13. I believe doctors at LH were responsible for infecting me with hepatitis C.

Addenbrooke's Hospital, Cambridge – 2000 to date

14. In about 2000, I moved to Cambridgeshire and transferred to Addenbrooke's Hospital (ABH).

Medical notes

15. In 2003, I first requested my medical notes from LH. Upon receipt of these, I have found that some records are missing. In particular, the hospital has not sent 6 years of liver test results taken in the 1980's which are relevant to this inquiry. I am informed by LH staff that these results have been misplaced and I find this difficult to accept.

16. The Skipton Fund refused to make an ex-gratia payment to me because they were not able to see the results of these liver tests which were carried out at the time when I believe I was infected.

Hepatitis C

17. In 1992 LH sent a letter to me advising that I was infected with Hepatitis C but they did not tell me when they found out. The doctors never gave me any information or advice about this infection and how it would affect me. Neither did they tell me what I should do help prevent me from spreading it to others.

18. In 1996 my girlfriend and I asked the doctors about my hepatitis C. As a result, LH arranged for us to be tested by a haemophilia nurse, **GRO-D** **GRO-D** who, having completed the tests, assured us that we were fine and the anti-bodies that were present in my body had successfully fought off the infection. She told me that I had natural immunity and I should consider myself 'very lucky'. After being assured of this, I married my girlfriend in 1997.

19. It became very apparent throughout my life that in fact, nothing about what had happened to me thereafter warranted "very lucky" status, especially after losing my brother, being denied compensation and facing considerable difficulties obtaining life insurance. By no means do I consider myself to be "very lucky".

20. I am disgusted about how the information was communicated to me because the doctors at LH left my parents in the dark. In 1996, when my girlfriend and I became more aware of hepatitis C, we went to LH in search of answers only to be told by the doctors that it was nothing to worry about.

21. In about 1997, after we married, my wife and I were seeking a mortgage and applying for life insurance. I found out that our applications were being refused because I was honest enough to admit that I was previously infected with hepatitis C. As a consequence, I had health insurance refused because of it. Afterwards, I ceased to have any trust in LH and did not believe what they told me. All my brothers felt the same.

Section 3. Other Infections

22. I do not think I was infected with any other viruses. The doctors at ABH did think that I was at greater risk of developing VCJD but I have not heard anything about this. I believe the treatment used was excessive and unnecessary especially as there were doubts regarding the safety of the blood products.

Section 4. Consent

23. I do not know whether it was necessary for doctors to treat me with FVIII products in the first place because my bleeds were only mild. I was also concerned that the doctors were treating me with FVIII for bruises. I believe such treatment should not have been necessary. The doctors at LH never asked my parents for their consent and they should have given them a choice.

24. As I became more aware, I found out about DDAVP. This product increases Factor VIII to a level to stop minor bleeds. I do not know whether this product was available to doctors to use on me at the time I needed treatment. If it was, I believe the doctors should have used it instead of FVIII products.

25. If the doctors had informed my parents of the risks of being treated with FVIII, they would not have allowed them to use the products on me.

(a) Hepatitis B – According to my medical notes, the doctors in 1984 were using Cryoprecipitate to stop any potential bleeding from the intramuscular hepatitis B vaccine. It follows from this that they must have carried out tests on me without my knowledge or consent.

(b) Hepatitis C – In 1992 LH told me about that I was infected with hepatitis C. It follows from this that the doctors must have carried out tests on me without my knowledge. It is unlikely that they treated me for it. If they did, it was without my knowledge or consent.

(c) Research - I do not know whether the doctors tested me for the purposes of research.

26. The doctors never gave my mother any information or any adequate information about the risks associated with Factor VIII products.

Section 5. Impact

27. I saw my brother suffer from various illnesses that were caused by the doctors before he died in 2010. I knew that [GRO-C] and this was unsettling for me as we were all very young and growing up in constant fear.

28. In the early to mid 1980's, there were occasions when I suddenly collapsed. This happened twice at secondary school, once when I was on a station platform and once when I was in the bathroom at home. I believe at the time my body's immune system was fighting off the infection and that is what was causing me to collapse.

29. I had to deal with the death of my brother, Graham, who had liver transplant and was detained under S.18 of the Mental Health Act 1983. He gave up and did not want to live anymore. I had to deal with the pain and the suffering he was going through. I believe I would have done better in school had I not been infected and if I did not have to worry about my brother's poor physical and mental health.

30. My mother noticed that my eyes [GRO-C] turned yellow. This was [GRO-C] teenage years. [GRO-C] going through a difficult time I believe this caused was mainly due to the treatment [GRO-C].

31. In 1992 when the doctors knew I was infected with hepatitis C, they pretended it was not significant. They told me to forget all about it as it 'was not a big deal' and that it was "something that haemophiliacs get" so that is what I did. They never gave to me any advice as to what I should do to manage it or what I should do to prevent the infection spreading to others. I was never called into hospital nor had the results explained to me.

32. It is only when I met my girlfriend that I started asking questions about my health. I had to deal with knowing that I was infected with hepatitis C not

knowing how it was going to affect me in the future. I consider that the onus was left on my girlfriend and I to find out. I am of the view that the doctors should have informed us and been more honest with us. It was only upon our insistence [REDACTED] GRO-C

[REDACTED] GRO-C

33. Whenever the doctors took out my medical file, it had lots of yellow stickers on it that said, 'danger of infection'. This was even though doctors had told me not to worry about the infection.

34. My infected status did not have an impact on any treatment.

35. My family and social life was not affected initially because the hospital had told us that the infection was not anything to be worried about. But this changed when I began to see how hepatitis C affected my brother.

36. When completing life insurance forms, I found that I was paying higher insurance premiums because of my infection.

Section 6. Treatment/Care/Support

37. I was not offered any treatment, care or any support from any hospital at any time.

Section 7. Financial Assistance

The Skipton Fund

38. In 2004, The Skipton Fund refused my application for payment because I was told I was "ineligible". In 2007, I made a further application but was still refused payment because there was "no evidence to suggest that the infection of hepatitis C progressed to the chronic phase". I am sure that this was because crucial medical records of my liver results for 6 years were

missing.

39. In 2008 my appeal against the decision was refused on the basis that the infection did not last more than 6 months.

40. To date, I have not received any money whatsoever because I do not have any medical records.

Section 8. Other Issues

41. I was involved in the 1990 American litigation but we never got justice. The pharmaceutical companies argued that the case should be heard in the courts of England and not the American courts.

Anonymity, disclosure and redaction

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

43. I wish to be called to give oral evidence.

Statement of Truth

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

Signed..

GRO-C

Steven John Towsey

Dated 28 February 2019