

Witness Name: Nancy Arabella Rybinska-Lambert

Statement No: WITN2800001

Exhibits: WITN2800002-008

Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NANCY ARABELLA RYBINSKA-LAMBERT

I, Nancy Arabella Rybinska-Lambert will say as follows:-

Section 1. Introduction

1. My name is Nancy Arabella Rybinska-Lambert. I was born on [GRO-C] 1989 and live at [GRO-C] Liverpool [GRO-C].
2. I live at home with my two children, [GRO-C] and [GRO-C]. I have no other family. My father and his parents, my grandparents have passed away.
3. I make this statement on behalf of my late father, Stephen Paul Lambert. He was born on the [GRO-C] 1960 and died on the 19/01/2009 at the age of 48 as a result of Hepatitis C (Hep C).
4. This witness statement has been prepared without the benefit of access to my late father's 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 Affected

5. My father had Hypodysfibrinogenemia, which is a rare hereditary fibrinogen disorder cause by mutations in one or more of the genes that encode a factor critical for blood clotting. It can change in severity from mild to severe depending on the fibrinogen in his blood count.

6. The blood products that he received were Fibrinogen Concentrate, Cryoprecipitate and FVIII. I believe my father first received FVIII in the late 1970s/early 1980s. However, throughout his life he had a combination of Cryoprecipitate and FVIII.
7. My father was part of the Haemophilia Society. As a child he attended Alder Hey Children's Hospital and he continued his treatment at Liverpool Royal Hospital (LRH). Dr Vanessa Martlew was his treating consultant.
8. I do not know the period of dates that my father was infected. It could be anytime from when he started to receive FVIII.
9. I do not believe that my father was given any information or advice beforehand about the risk of being exposed to infections regarding the Cryoprecipitate or FVIII that he received. It is only later that there is a medical record to Dr Hay, dated 18 March 1992 which confirms that because of the past treatments that he received, he needs to be tested for Hepatitis B (Hep b), Hep C and HIV. A copy of this medical record is exhibited at **'WITN2800002'**.
10. My father was infected with Hepatitis C (Hep C) and he was infected with the above blood products that he received.
11. On the 8 May 1992 after having the above tests my father was told that he tested negative for HIV and Hep B, but he tested positive for Hep C. I believe that the doctors spoke to him about the Hep C, but I do not know whether adequate information, if any was provided. He never once mentioned to me that he knew that there was a risk of infection if he used FVIII. A copy of the above letter is exhibited at **'WITN2800003'**.
12. I believe my father may have lived with Hep C for many years before he tested positive. The medical records that I have been given are missing a lot of information and skip a lot of dates. However, what stands out to me is that he attended the hospital many times with a problematic ankle and asked a lot of questions about the arthritis and bone cysts at the age of 18 years. He

attended the doctors numerous times with ankle pain and he was informed he had osteoarthritis although there had been no trauma or history of bleeds to this area. I remember his ankle always being very painful with purple swelling. I believe this was very rare at the age of 18 and I therefore believe the above symptoms were as a result of the Hep C and that he could have been infected with Hep C from the age of 18.

13. I believe that my father should have received information about Hep C and the blood products that he received a lot earlier.

14. I am unable to comment about how the results of the test were communicated to him.

15. I do not believe that my father was given any information about the risks of others being infected as a result of his Hep C.

Section 3. Other Infections

16. I do not know if my father received any other infections other than Hep C. If he had, I was not informed of it.

Section 4. Consent

17. I believe that my father was tested without being given adequate and full information as there are no medical records about being counselled over the impact the Hep C would have to his life.

18. My father was tested for HIV in 1985 and luckily he tested negative for it. However, the blood test record does state that he had American Fibrinogen as a child. It is therefore possible that he was tested and treated for the purposes of research. A copy of the blood test record is exhibited at 'WITN2800004'.

Section 5. Impact of the Infection

19. I believe my father's health was used against him. I was taken into care and my father ended up in a custody battle, which he won. I later moved to

Liverpool to live with my father and his parents. He had pressures of being a sick, single parent. My father also had suicidal tendencies as well as depression as his benefits were taken away from him when I was a teenager.

20. As a result of the Hep C my father suffered further medical conditions. He suffered from chronic kidney disease stage 3, hypertension, left renal artery stenosis, cerebral haematoma and arterial sclerosis.
21. He suffered from the stigma that was attached to Hep C and he was terrified about people finding out that he was infected. He lost a lot of friends and he did not have a social life. He was unable to find work as a result of the Hep C. He was the only person in the family who was relied upon to go out and work and he was unable to do so.
22. He suffered an injury to his leg and it was amputated. The prosthesis was not fitted correctly and he would suffer bleeds when walking or standing. He was terrified if he had a bleed and terrified about what people would think of him if they found out he had Hep C.
23. As a result of the infection, he suffered from chronic fatigue, extreme weight loss and weight gain due to the medications that he had. He also suffered from painful migraines, swelling of the hands and skin rashes. He also developed eyesight issues and had to wear glasses. He had a yellow colour in his eyes and face and I believe the above symptoms were as a result of the infection.
24. In the mid 1990s, his medical records confirm that he most certainly contracted Hep C from the fibrinogen treatments, cryoprecipitate or FVIII. It also states that my father was unwilling to have a liver biopsy because there was a risk of bleeding. This was fully understood by doctors as he would have required a lot more treatment. The doctors were unable to confirm the degree of hepatitis due to this.
25. In 1995 my father was offered and started the Interferon treatment and was advised of the side-effects from the treatment. However this treatment did not clear the Hep C. On examination he was anicteric.

26. In the late 1990s my father was interested in exploring the possibility of combined anti-retroviral therapy with Ribavirin and Alpha-Interferon. This was discussed with the doctors. However, I believe my father was told that there was a possibility that this treatment may affect the arterial sclerosis that he had. He therefore decided not to have the combination therapy due to the risks it had to the arterial sclerosis.
27. There is a medical letter dated 12 March 2001 to Dr Singh, which confirms that my father attended a doctor's appointment and it was suggested that he needs to have antiviral treatment as the liver enzymes were mildly elevated from the test that he had in February 2001. A copy of this letter is exhibited at 'WITN2800005'. My father's liver enzymes were checked on a regular basis and it continued to elevate for a couple of months.
28. A medical letter dated the 14 November 2001 to Dr Singh confirms that he started the combination treatment for Hep C. Since he has started the combination treatment for Hep C he experienced considerable anorexia. A copy of this letter is exhibited at 'WITN2800006'.
29. During the above treatment a medical letter dated 13 June 2002 address to Dr Singh from Dr Martlew confirms that my father suffered severe nausea and profuse vomiting and felt that he was unable to tolerate the treatment. The doctors were anxious to avoid strenuous retching in view of the spontaneous intracranial haemorrhage, which he sustained about six months ago. The doctor therefore advised my father to discontinue the treatment. A copy of this letter is exhibited at 'WITN2800007'.
30. My father's health continued to deteriorate as a result of the Hep C and he died in 2009. Many of the health conditions and symptoms he was admitted with were linked to Hep C, as previously stated.
31. I believe the infection caused my father to suffer more than he needed to. He was taken away from me prematurely at the age of 48. I was only 19 at the time and I was left living with my elderly grandparents. My grandfather was unable to cope with the pain of losing his son and I believe as a result he

died a year later. My grandmother suffered from horrendous depression and nightmares.

32. My father in his later years also suffered from great depression, wanting to give up. As previously stated, he had suicidal tendencies. He was on benefits and struggled getting the support that I believe he was entitled to. My grandmother told me a few years before she died that at that time of his life he wanted to commit suicidal.

33. The impact of my father's death still affects me today. I do not have any living family members. I have two children and they did not get to meet their grandfather and that really upsets me.

34. My father suffered work-related effects as a result of the Hep C. He worked as a bar manager but had to give the job up due to the risk of infection to others. He was then put on benefits. As a result, he struggled financially.

Section 6. Treatment/care/support

35. I do not know if my father faced any difficulties or obstacles in obtaining treatment, care and support.

36. I do not believe my father received any counselling or psychological support. I have not received any counselling or psychological support as a result.

Section 7. Financial Assistance

37. My father was put on benefits from 1992.

38. I believe he also received a small payment of £5,000 from the Skipton Fund in or about 2004. I believe this is all the financial assistance he received.

39. I did not receive any financial assistance and I do not believe my grandparents received any.

Section 8. Other Issues

40. There is a medical letter dated the 4 April 2001 which confirms that my father was offered to try out the Scottish Fibrinogen concentrate instead of cryoprecipitate for future treatment. I know my father was allergic to cryoprecipitate and it makes me think as to why he was not offered Scottish Fibrinogen sooner. As previously stated either or both cryoprecipitate which has FVIII or FVIII treatment alone infected my father with Hep C. A copy of this letter is exhibited at 'WITN2800008'.

Anonymity, disclosure and redaction

41. 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.

42. I wish to give oral evidence to the Inquiry.

Statement of Truth

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

Signed

GRO-C

Dated

26/04/19