

Witness Name: Wendy Clark

Statement No: WITN1153001

Exhibits: WITN1153002

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF WENDY CLARK

I, Wendy Clark will say as follows:-

Section 1. Introduction

1. My name is Wendy Clark. My date of birth is GRO-C1955 and I live at GRO-C
GRO-C Cambridgeshire, GRO-C
2. I make this statement on behalf of my late husband, Mr Raymond Christopher Smith, who was born on GRO-C1953. My husband died on 7/01/1986 aged 32 from pneumonia as a result of AIDS.
3. This witness statement has been prepared without the benefit of access to my late husband's 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.
4. My son, Christopher Raymond Smith (WITN1711001) has also produced a witness statement for the inquiry.

Section 2. How infected

5. Raymond was diagnosed with severe Haemophilia A from birth; he was the first to be diagnosed in his family. Neither of Raymond's parents were haemophiliacs.
6. Raymond had cryoprecipitate treatment for many years until Factor 8 (FVIII) became available. I met Raymond at the age of 16 and I recall he administered cryoprecipitate at home. I am not sure when Raymond started using FVIII but I believe it was around the mid 1970s/ early 1980s. Details of treatments that Raymond received are exhibited at 'WITN115302'.
7. Raymond attended Addenbrooke's Hospital (AH) from the mid 1960s and he was under the care of Dr Charlmers. When Dr Charlmers died, he was under the care of Dr Seaman. Before this, Raymond lived in Ilford as a child but I am not sure which hospital he attended.
8. I believe Raymond was given contaminated FVIII in the mid 1970s/early 1980s.
9. I had my youngest son, Antony, in June 1984, so I believe Raymond was not infected then. Therefore, I believe Raymond became infected in or about 1984 or 1985 or just after Antony was conceived in the late 1983.
10. In or about 1985 another friend of Raymond who was also a haemophiliac rang Raymond and asked if he knew anything about the blood products, which we did not. Raymond and I then telephoned the hospital and made an appointment. We were told not to worry because it had all been blown out of proportion. My husband told the hospital he would rather go back to cryoprecipitate if there were any problems; I was present when this discussion happened.
11. When Raymond switched from cryoprecipitate to FVIII no information was provided beforehand about the risks involved.

12. I believe Raymond was told he was HIV positive in late 1985, but I was not at that appointment. I recall that he came home from the hospital and said he had HIV.
13. We were never given any information about HIV, Hepatitis C (Hep C) or Hepatitis B (Hep B). He was just given AZT tablets to take.
14. Around the Christmas period of 1985, Raymond became very ill, so we telephoned the hospital and they booked an appointment for the 2nd of January 1986. As soon as Raymond went to the appointment he was put into isolation. I asked why he was in isolation and they said it was because he had HIV. On the 6th of January 1986 Raymond and I was told that the HIV had developed into AIDS. It was at this point that they said it would only be a matter of time before he died. There was nothing more that they could do. He died the following day.
15. After Raymond had died the doctor wrote me a letter saying how sorry she was. When I think about this now, I believe this is a strange thing for a doctor to do. Unfortunately, I do not have the letter anymore and it is not in the notes I have been provided with. I was also told that Raymond was one of the first haemophiliacs who died from HIV.
16. I do not believe Raymond was provided with any adequate advice or information in relation to the HIV or Hep C.
17. I believe information should have been provided to both Raymond and I earlier.
18. I think the way we were told about the infection was awful. I kept trying to find out more information about the infection but everything was so vague. I did not know Raymond had full blown AIDS until the day before he died. As far as I was concerned he was just in hospital for more tests. At 7am on the 6th January 1986, I received a telephone call saying that I needed to get to the

hospital because Raymond might not make it. When I arrived at the hospital Raymond was slipping in and out of consciousness so I never really got the chance to speak to him. Christopher thought Raymond was just going in for a normal blood test but he never came out again. My sons never got a chance to see their father again. It was an absolute nightmare. Getting that phone call will be with me for the rest of my life. Nearly 33 years have passed and I can still recall every detail from that day.

19. Raymond and I were not given any information about the risk of infecting others. Raymond did say to me that we had to be very careful. Our sex life just stopped there and then because Raymond was quite poorly anyway.

Section 3. Other Infections

20. As far as I am aware Raymond was not infected with anything other than HIV, Hep B and Hep C.

Section 4. Consent

21. I believe Raymond was tested without his consent, knowledge and without adequate information. As far as we know he was only tested for HIV when we requested it. He was having dental treatment at the time and the dentist told him to have a blood test. However, Raymond's medical records shows that he tested positive for HIV in January 1985. The blood tests also show that he tested positive for Hep Bc antibody. I believe that Raymond had no knowledge that he was being tested for HIV or Hep B. I was not told until late 1985 that Raymond had HIV.

22. I also believe Raymond was tested for the purposes of research because he was one of the first to be diagnosed in our area. Raymond always attended the hospital for regular blood tests for his Haemophilia but I did not know what the tests were for.

Section 5. Impact of the Infection

23. The biggest physical impact was Raymond's weight loss. I believe it started in or about June 1984. He was a 36 inch waist and dropped to a size 30 inch waist within 6 months. He lost his appetite and did not want to eat. I was shocked to see how much weight he lost in such a short period of time.
24. Raymond struggled to sleep at night because he was so worried about his health. He did not know why he was so ill, this terrified him. Raymond and I had two young children and leaving the children without a father was his biggest concern.
25. Raymond died so quickly after being diagnosed. I do not know if there were any further medical complications. I believe Raymond had cirrhosis, but I cannot prove it.
26. Raymond received AZT treatment in late 1985 for the HIV but this was the only treatment that he had. I do not believe Raymond had any problems getting the AZT treatment, but we were told this was the only treatment available. The treatment made Raymond very sick.
27. When Raymond died it was unbelievably difficult. I was left as a single mother with two sons aged 8 and 18 months. My coping mechanism was to block everything out. It has only been since the Inquiry started that I realised how much Raymond's death had affected Chris. This is the first time Chris has been opened about how he feels. The last time Chris saw his father was when he walked out of the house on the 2nd of January 1986.
28. Living with someone who had HIV was very difficult. Raymond stopped going out because he did not want people to ask why he was losing weight. He could not go out and do things with his children, so the children also missed out. When Raymond was told that he had HIV he was terrified that he might infect the boys. My parents were equally as worried about me getting infected. It had a devastating effect on all of the family.

29. The hospital just kept apologising for Raymond's death. They then asked the boys and I to be tested about a week after Raymond's death. GRO-C

GRO-C

30. The stigma was very bad at the time so we did not tell anyone that Raymond had HIV. Raymond felt very isolated because in 1985 no one talked about AIDS. Both sets of parents and Raymond's siblings were the only family members who knew of his situation. Raymond did not want anyone to know (including the boys) because he was worried if too many people found out it would affect the children. The media was a nightmare. I remember seeing people who had their houses vandalised. Even though Raymond got HIV through blood products it would not have made a difference. We therefore kept his status to ourselves.

31. Since the Contaminated Blood Inquiry started people have said to me that they had no idea what my family went through. People ask why I did not talk to them about it, but I just said I was too scared to talk to anyone. I feel that I am now able to talk about it with my friends and family.

32. Our finances suffered because of the infection. Raymond could not work when he found out about the HIV. Raymond's father was trying to keep the business going but it was very difficult. I was then on my own for 20 years with two children to support. The business also went downhill and I believe it was because my father-in-law could not cope.

Section 6. Treatment/care/support

33. Raymond and I did not get much care and I do not believe there was enough support.

34. Raymond was not offered any counselling when he was diagnosed with HIV and I believe that had he been offered it, it would have helped him understand and manage his infections.

35. After Raymond died no counselling was offered me until after the Macfarlane Trust was established. Chris was offered counselling, but I did not have any.

Section 7. Financial Assistance

36. When Raymond died there was no financial assistance at all. The Macfarlane Trust got in touch with me through the Haemophilia Society.

37. I have received some financial support from the Macfarlane Trust, but I cannot find any paper work, so I do not know what I received. I believe I probably destroyed the paper work because I never wanted to see it again. I believe I got a monthly sum from the Macfarlane Trust when the Trust started, but I cannot remember how much. I do not believe I got a lump sum payment. I do not believe I had any problems applying for the monthly payments.

38. Approximately 18 months ago I received £20,000 from the Skipton Fund. We did apply for the Stage 2 payment, but because the majority of the notes are missing, we could not prove Raymond qualified for Stage 2 payment.

39. I only found out about the Skipton Fund 18 months ago because one of Chris' friends told us.

40. I did not face any difficulties when I applied for the £20,000 from the Skipton Fund.

Section 8. Other Issues

41. The hospital said they cannot find all of Raymond's medical notes. I find this very strange.

42. I trusted these people 100% but they just let us down. The way they treated us was disgusting.

Anonymity, disclosure and redaction

43. 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.

44. I do not wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed: GRO-C

Dated 28.1.19

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Virology Results

28/10/1976	Australia Antigen Negative
11/08/1980	Hep B – Antigen - Negative Antibody – Negative
07/05/1981	Hep B – Antigen - Negative Antibody – Negative
16/10/1984	Hep B – Antigen - Negative Anti - HBc – Positive
10/01/1985	Hep B – Antigen - Negative Hep Bc – Ab Elisa Anti HBc – Positive Hep Bs - Ab – RIA anti-HBs – results equivocal HTLV-111 Results to follow
23/01/1985	Hep B – Antigen - Negative Hep Bc – Ab Elisa Anti HBc – Positive Hep Bs - Ab – RIA anti-HBs – results equivocal HTLV-111 - Positive