

Witness Name: E R Kuhni
Statement No: WITN3377001
Exhibits: WITN3377002-4
Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ELVIRA RENATA KUHNI

I, Elvira Renata Kuhni, will say as follows:-

Section 1. Introduction

1. My name is Elvira Renata Kuhni of GRO-C Switzerland. My date of birth is GRO-C 1959. I have three sons, one daughter and one grandson. I used to work as a nurse in a care home and I am now retired.
2. I make this statement on behalf of my late husband, Malcolm Alexander Russell, who was born on GRO-C 1956 and died on 12 March 1990 aged only 33. Malcolm was infected with Hepatitis B and HIV as a result of receiving contaminated blood products and subsequently passed away as a result of AIDS related illnesses.
3. **This witness statement has been prepared without the benefit of access to my late husband'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.

4. Malcolm was involved in the 1991 litigation and I understand that the solicitor that represented him had been provided with extensive medical records but never returned them upon conclusion of the case.

Section 2. How Affected

5. Malcolm suffered from severe Haemophilia A. I understand that he received Factor VIII concentrate and he had home treatment with Armour Factorate.
6. In 1982, before I met Malcolm, he was involved in a motorbike accident and he had to have several operations to repair his leg and he received Factor VIII on multiple occasions.
7. Malcolm was a patient at the Haemophilia Centre in Oxford. His consultants were Dr Rizza and Dr Matthews.
8. Malcolm was infected with Hepatitis B and HIV as a result of receiving contaminated blood products.
9. After Malcolm died contemporaneous notes, draft letters and letters were found and I will refer to these in my statement and exhibit where relevant. Malcolm was a very intuitive person and had suspicions that something wasn't right very early on and he kept diaries of what happened to him.
10. I refer to Exhibit **WITN3377002** which is a copy of his death certificate which records the causes of death as: 1(a) Bronchial Pneumonia, 1(b) Cryptosporidial Infection, 1(c) HIV Infection and Haemophilia. It also states that he died as a result of an accident. I really do not know why that would be listed as a cause of death because his accident had nothing to do with his death. I only noticed that it was on the paperwork in the autumn of 2018.
11. I refer to Exhibit **WITN3377003** which is a copy of the Inquisition into Malcolm's death. It states that, "*He suffered from Haemophilia and between*

the 22.10.1979 and 31.7.1984 he contracted an HIV infection as a result of being given contaminated blood products."

12. On 1 June 1985 we attended a meeting with Dr Rizza regarding concerns that testing was being undertaken without his knowledge.

13. Malcolm recorded in his diary that the date of his first positive test was the 3rd October 1984 and he would have been 29 years old. In August 1985 Malcolm was asked to attend a meeting with Dr Rizza in which he was told that he had tested positive for HIV. We talked about it but we did not really understand what it meant. In the beginning it was very much played down and we were told by the doctors not to worry. I do not think even the doctors understood the damage that it caused.

14. I do not believe that the doctors provided Malcolm with adequate advice in relation to his infections. I recall we were advised to use condoms and Malcolm was advised to be careful when administering treatment at home.

15. I believe that Malcolm should have been provided with information earlier.

16. I have reviewed Malcolm's personal diary and there is an entry where he received a telephone call in October 1986 from Dr Matthews in regards to a faulty batch (number A40510) of Factor VIII that had been issued to him on 27 July 1986. By this point he had used 16 of the 20 bottles that had been given to him.

Section 3. Other Infections.

17. To the best of my knowledge Malcolm was not exposed to any other infections.

Section 4. Consent.

18. In Malcolm's diaries he wrote that he had most definitely been tested without his knowledge and without his consent. The notes in his diary refer to a number of tests as follows which could be the immunity tests:

- 3/10/84 start tests at Churchill for Aids tests - 2 years
- Hepatitis B Pos July – Oct 83
- Started heat treated factor eight end of Dec 84
- 15.1.85 2nd tests for Aids immunity (skin tests)
- Also 3rd Blood test for new heat treatment material
- 16th July 4th test + 6 monthly check up
- 17th Oct 85 5th test
- Immunity Survey positive last 9 months
- 13th February 86 6 test HVTL3 positive last 12 months
- 5th June 7 test HTVL.

19. I do not know whether Malcolm was tested for the purposes of research. He often told me that he felt like he was a guinea pig.

20. The letter at **Exhibit WITN3377004** states that by the time of the letter, approximately June or July 1985, they "*have now tested about 300 patients, some only once or twice, some as often as five or six times*". The logistics involved in longitudinally testing 300 patients suggests that testing took place over an extended period of time. Dr Rizza appears not to tell Malcolm why the tests were being carried out and it was highly likely that Malcolm had therefore been tested on numerous occasions by this point.

21. Once Malcolm had realised there was no alternative source of plasma he became very angry. He was a severe haemophiliac which resulted in a close relationship with his doctors. When he found out that the doctors had kept information from him he was very angry and he felt very let down.

Section 5. Impact

22. In 1985 when we found out that Malcolm was HIV positive we were shocked because he did not show any symptoms and he generally felt fine.
23. We understood that Malcolm was HIV positive but at that time we were not that stressed or worried about it particularly because the information and the way in which the news was conveyed to us was highly played down.
24. It wasn't until the summer of 1988 when Malcolm suffered from pneumonia that we realised what we were actually dealing with. This was a turning point because before that illness it was easy to pretend that everything in our lives was fine. The pneumonia came from nowhere and his health suddenly deteriorated. The doctor told us that Malcolm had developed AIDS and from that point our lives changed forever.
25. Malcolm was treated with AZT and he suffered with negative side effects including thrush in his mouth, nausea and vomiting numerous times throughout the day. As a result of the horrendous side effects Malcolm intermittently stopped taking the AZT treatment. He always wanted to return to the treatment because he felt that the treatment was his only option.
26. During the Christmas of 1988 Malcolm developed anaemia and he became extremely weak. I do not recall the treatment he received at that time.
27. By the early spring of 1989 he developed a cryptosporidium infection which made him sick with diarrhoea. Initially we thought it was the AZT treatment again but it wasn't and Malcolm experienced a huge weight loss.
28. During this time we noticed an extreme deterioration in his health both physically and mentally. He became depressed and we could no longer spend time pretending that everything was fine. We both knew that he would not get better.

29. In the autumn of 1989 Malcolm suffered from excruciating lower back pain and the doctors prescribed pain relief for what turned out to be the beginning of renal failure.
30. Before the Christmas of 1989 Malcolm became really ill and had to go into hospital on numerous occasions. During that time he received strong painkillers. At the same time my father was battling with cancer in the final stages of his life and he died after Malcolm in June 1990.
31. As my father was so ill Malcolm insisted on visiting my family in Switzerland after Christmas even though he was so weak and ill himself. We had to return back home after a few days due to him deteriorating and with that he had a total mental breakdown. He was immediately admitted to the Churchill where they also started him on antidepressants. After about 5 weeks he felt slightly better and he came home where I nursed him until he died.
32. It was a very challenging time as he was so weak and could not walk anymore. Malcolm had always been such an independent person and he must have felt awful and undignified. I know he found it very difficult and frequently lashed out.
33. While at home during the lead up to his death the cancer staff were involved with his care because they were used to dealing with such situations. Malcolm used to refuse their support and was not always polite to them sending them away. One of their doctors changed Malcolm's medication which resulted in better pain control and less confusion. It was a big help to us all as the GP who visited daily often felt out of his depth.
34. I loved and admired Malcolm and we had a good life together. It was so difficult to watch him go through the illness and see how much his character changed as a result of the frustration and the pain caused by the HIV.
35. Malcolm worked for Oxford County Council and they were very understanding when he went off work sick. He was grateful for that job because he had been unemployed for quite sometime prior to that. The Haemophilia prevented him

from getting a better job despite being qualified. Malcolm didn't apply for a job for a long time because he was scared that he would have to disclose his medical history.

36. Malcolm found it very frustrating because he wanted to continue with his accounting qualification but was prevented from doing so due to his ill-health. He was such a determined person and he continued working even when he was in a lot of pain. I think it was towards the latter part of 1989 when he stopped working. It was so difficult and in the last two years of his life he had completely changed.

37. The Haemophilia Centre encouraged us to tell people that Malcolm had suffered with cancer and that's exactly what we did. We told everyone that he died of cancer. I can only think that the Haemophilia Centre were trying to protect us from the stigma that was associated with HIV and to ensure that people would not isolate us.

38. Once he had contracted AIDS I know that Malcolm would not have kept quiet.

39. I have only recently told my son the truth about what his father really died from. It was forced upon me because of this situation which of course is a good thing. Somehow the years had gone by and it never seemed to be the right time for this sad revelation. I also wanted to protect him. My son really struggled once I told him and I felt he preferred the idea of his father dying from cancer.

40. Having a young child at the time made life very difficult for us. In the beginning we were both very shocked and we both wanted to get on with our lives. We had a few very good years after his HIV diagnosis. From the time he developed pneumonia our life had changed and when he was diagnosed with full blown AIDS he was very poorly.

41. Malcolm was very concerned about me and our little son Jeremy. Malcolm worried that Jeremy might become an orphan. It was distressing for us both having to watch Malcolm sailing away. He was getting very angry towards the

end of his life and as his wife I suffered a lot which was I found very difficult to deal with whilst also trying to look after our son.

42. Before the AIDS diagnosis we were a very happy little family. We would watch our friends go onto have their second child but we were unable to. We felt sad that we could not give Jeremy a little sister or a little brother and we both felt heartbroken that we could not have another child.

43. After Malcolm passed away I was left on my own with Jeremy. Malcolm worried about leaving me and thought that I would go back to Switzerland. But I had so many good friends in England and I went back to work which meant that I could provide for Jeremy and look after him.

44. I was not ready to let go of Malcolm and I would often go to his grave and speak to him.

45. I had another relationship which did not work out but I have a lovely daughter from this relationship who is 25 years old now. Jeremy loved having a sister when she was born.

46. After approximately 11 years I moved back to Switzerland and I remarried. Jeremy has settled very well in Switzerland and has made a life for himself there.

47. The impact of Malcolm's infection and subsequent death on my life was very bad. It was good that I had Jeremy and that I had a child to look after because it gave me something to get up for in the morning. I had to try and stay happy and show him love.

48. It has affected Jeremy as he grew up without his father but I also think he has grown up as a happy child. I had a very good brother in law and Malcolm's best friend continued to be a family friend who both supported us. It also meant that Jeremy had strong male influences and good men to look up to.

49. I remarried in 2002 and we had two more boys who are now aged 14 and 16. I also have a lovely grandson who keeps my hands full.

Section 6. Treatment/Care/Support

50. I do not really have any comments to make in relation to any obstacles to treatment that Malcolm received. It was disappointing for Malcolm when his relationship with Dr Rizza and Dr Matthews broke down because Malcolm had really respected them. It was difficult for Malcolm when he realised the truth.

51. I became friendly with a nurse from the Haemophilia Centre and I would speak with her and confide in her. Other than that I was never offered any psychological support.

Section 7. Financial Assistance

52. Financially it was very difficult throughout our life because Malcolm was unemployed for many years and when he went into employment we still struggled. We lived on a very tight budget.

53. In 1989 Malcolm received £20,000 ex-gratia payment from the MacFarlane Trust.

54. Before Malcolm was diagnosed with HIV he set up a life insurance policy. However, it was at a much lower rate because he had Haemophilia. I received approximately £34,000 following his death which I believe was at a 40% rate.

55. Malcolm had started the 1991 litigation which resulted in a lump sum payment of £60,000 and I used this to buy a small house for Jeremy and I to live in.

56. I have not received any payments from The Skipton Fund.

Section 8. Other Issues

57. Malcolm would be mortified if I did not fight for him and I want to do that because I am angry that the Government wanted to save money at the cost of other people's lives.

58. I want to know why the Government ignored knowledge from the US about the risk of infection. People were aware that there was a risk of contamination from using this blood and I want to know why they took that risk and why they played with peoples lives.

59. It is difficult to know and say what would have happened with Malcolm, he may have passed away as a young man anyway due to his haemophilia but maybe he would still be alive today.

Anonymity, disclosure and redaction

60. I do not wish to remain anonymous.

61. I do not mind giving oral evidence if the Inquiry felt it was necessary.

Statement of Truth

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

Signed... GRO-C

Dated... 9.12.2019