

Witness Name: Jo-Anne Cohrs

Statement No: WITN1162001

Exhibits: 0

Dated: February 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF JO-ANNE COHRS

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I, Jo- Anne Cohrs will say as follows:-

#### Section 1. Introduction

1. My name is Jo-Anne Cohrs. I was born on GRO-C 1959 and I live at GRO-C  
GRO-C Tyne and Wear, GRO-C
2. I write this statement on behalf of my late husband Keith Proud, born on GRO-C  
GRO-C 1949 and died at the age of 38 on 6 March 1987. Keith died from Cerebrovascular Accident and AIDS after receiving contaminated Factor VIII blood products.
3. We met in 1980 and we married in December 1983. I remarried after Keith's death and had a child and I now live with my daughter. I am not working but I do various volunteer work.
4. This witness statement has been prepared without the benefit of access to my late husband's full medical records.

#### Section 2. How Affected

5. Keith had severe Haemophilia A. I believe he was initially treated with Cryoprecipitate. From the mid 1970s to the mid 1980s I believe he was

treated with Factor VIII (FVIII). He used to self-administer FVIII at home usually on alternate days and as and when he had a bleed.

6. At one point during the late 1960s or early 1970s, I recall that Keith was on an experimental drug related to pig's blood. I believe this was as part of a research, but I am not sure what kind of research.
7. Prior to 1984, Keith was under the care of Dr Peter Jones at the Newcastle Haemophilia Centre at the Royal Victoria Infirmary (RVI). From 1984 until his death in 1987, he was under the care of Dr [GRO-D] at Addenbrooke's Hospital (AH).
8. I do not believe that Keith has had any blood transfusions. He never used to drink or have a risky lifestyle. I therefore believe he contracted these infections through FVIII products.
9. I believe that Keith was not provided with any information or advice beforehand about the risk of being exposed to infection when using FVIII.
10. As a result of using FVIII, Keith contracted Hepatitis B (Hep B), Hepatitis C (Hep C) and HIV. I believe he was told that he had Hep B in or about the late 1970s. I am not sure when he tested positive for Hep C.
11. In or about 1984, Keith had a very bad cold, which later turned into Pneumonia. At this point we started to hear about the HIV in the media and therefore contacted AH who tested him.
12. In January 1985, we received a letter through the post stating that Keith had tested positive for HIV. We did not know what to think. We therefore booked an appointment to see Dr [GRO-D] at AH to try and obtain more information about the HIV as the media was scaring us.
13. We had a few verbal consultations with Dr [GRO-D] about the HIV and was provided with very little information. I believe we were not provided with adequate information. We went into hospital regularly once every two months

to try and get more information about HIV, but we were only provided with information in dribs and drabs and never got any concrete information.

14. I do recall being told not to have a marital relationship with each other or be intimate. We did take precautions as we did not want to bring a baby into this world with a possibility of contracting HIV. I was even told to use gloves around Keith. When we attended hospital appointments at AH, the doctors told me to get myself masked. This was really upsetting as I loved him and he was my husband. I did not care about being infected, so I did not treat him any differently.
15. In mid 1985 or 1986, I found out about Keith's Hep C diagnosis, which I believe was called non-A non-B hepatitis by reading a note that a Haematologist had left out on his desk during a routine check up at AH. It came as a surprise to both of us. We did not question the doctor further on it, as we believed that if it was concerning then the doctors would have spoken to us about it. At the time the doctor spoke to us about possible treatment for HIV.
16. We were more concerned about the HIV rather than the Hep C at the time due to the lack of information about Hep C. No information was provided to us in relation to Hep B and Hep C.
17. We did not understand the significance of Hep B or Hep C at the time, as we were already overwhelmed about the HIV. It just went over our heads as the doctors did not provide any information about the seriousness of Hep B and Hep C.
18. I believe we should have been provided with some information earlier just to help us understand it.
19. I believe Keith's HIV diagnosis should have been communicated in a different way. It was quite distressing to be told in a letter just after Christmas that he

was HIV positive. We would have liked a consultation about his test results with the doctors.

20. I recall a doctor at AH saying that since Keith did not do drugs or drink alcohol, the only explanation for the infections was that he contracted it from the FVIII treatment that he had over the years. Keith had also known some of his friends from RVI who were also treated with FVIII and diagnosed with HIV and Hep C.

### **Section 3. Other Infections**

21. Keith suffered from other conditions related to his HIV and Hep C, such as Candidiasis, Kaposi's Sarcoma, Pneumocystis Carinii/Jirovecii, Ataxia and Continual Diarrhoea.

22. A year before he died, he also started to show sign of cognitive loss. He was not tested for this but the doctor said it was Ataxia.

23. Keith took so many anti-fungal medications such as Nystatin for his fungus infection in his throat which caused a stomach ulcer.

24. He picked up pretty much any infection due to his weakened immune system caused by the HIV.

### **Section 4. Consent**

25. I do not know whether Keith was tested without his knowledge and consent. We found out about the HIV in 1985 and I am not sure whether the hospital knew prior to this.

26. It was difficult to say how much the medical profession knew at the time. I believe they knew this was going to develop into a catastrophic disease for the haemophiliac population.

27. I believe that Keith definitely was tested and treated for the purposes of research. In about 1986, at AH, a Haematologist called **GRO-D** came up with a theory that if he was given more contaminated blood products that had HIV it would boost his antibodies to start fighting off the infection, like being treated with a live virus. He had blood tests to see if the theory worked, but it did not. I still do not understand this theory.

### **Section 5. Impact of the Infection**

28. Keith's infections had a huge mental impact on him. He went from being a confident, newly qualified lecturer to someone who had lost his strength and not being able to teach his students anymore. He eventually had to leave his job.

29. We first lived in a teachers' flat provided by the local authority, then had to live in a house with a stair-lift as Keith could no longer manage the stairs. He was wiped out and very tearful. I was there for him and I knew deep down that he worked hard and that was upsetting.

30. It took him 4 years at university to become a lecturer and to know that his health was deteriorating made him extremely depressed.

31. When Keith first received the letter about the HIV status, he sat in silence for a few hours. He went off on his own and cried and we were both tremendously shocked. It was a bombshell for days.

32. Both of our families lived in North East England and we lived in the South of England so we never shared our troubles with them. Keith did not want to worry his elderly parents. We did keep in touch with them but did not tell them how dire things became. We were both strong Christians, so relied on our faith in God.

33. Our church was very supportive. Keith could not drive his mobility car and I did not drive at the time so at least 2 people from the church would telephone everyday to ask if we needed a lift to the church, shops or even to AH which was about 25 miles round trip. I could not have coped without them.

34. My social life was pretty much just at home with our puppy and kitten. I would say I am a strong person but in my private times back then was just curling up and crying.
35. Prior to when Keith was infected, we went on camping trips, on holidays, tours and had friends from college come over. We were heavily involved in the music at the church. In the space of just 6 months, we went from being very active to doing nothing. We lived a normal life prior to Keith's diagnosis even though he had Haemophilia.
36. In early 1985, Keith had an infection in one of his teeth, so we went to the local dentist (prior to Keith's infections he was always treated at the local dentist). Out of courtesy, we told the dentist that Keith was HIV positive. The dentist told Keith to come back at the end of the day for his treatment. When he went back, he said he did not want our family to be registered with his surgery and that we should find another dentist. This was very upsetting for both Keith and I. We did go to the hospital for all other dental treatments. However, the doctors at the hospital treated us the same way. Although Keith was treated, he was told to come back at the end of the day for his treatment. I also faced difficulties when I needed some dental treatment. I told the dentist that I do not have HIV, but he still refused to treat me. I did not expect the dentist to react this way. This really upset me and annoyed me.
37. Towards the end of 1986, Keith had Ataxia and mentally he was deteriorating and he often got confused. It was very difficult as I did not understand the development of his Ataxia. It was dawning on me that he was losing his mind. When he was physically ill, we would still talk about his college days and was able to have a normal conversation.
38. In or about March 1987 Keith walked out of the back door in our house and tripped on a step resulting in a concussion. I called the local ambulance service and they turned up in full white suits and took him to Lister Hospital in Stevenage. He was returned home with a plaster to his head within 30

minutes. He was in more of a mess when they returned him than he was before he was taken to the hospital.

39. Our Local GP, Dr Heelis came to the house and advised me to put Keith to bed. During the night, he fell into a coma. I then called Dr Heelis, who was very kind and understanding and he referred Keith to AH where he spent his final days. Keith never regained consciousness from the coma.

40. It made me angry that Lister Hospital neglected Keith and did not keep him there even though he had a very serious fall. I believe they neglected him because of his infections.

41. I do not think the doctors at the time knew much about what treatments to give. Keith had ongoing symptoms that resulted from the infections and required ongoing medication. I do not consider his body could have taken anymore medication. He took a lot of pain killers, anti-fungal medication and it was mentally difficult for him to take so much medication.

42. I do not believe that Keith received any treatment for his HIV but when he got symptoms as a result, he was in hospital for about 2 or 3 months. It was very depressing.

43. After Keith's death, the funeral director of the company that handled his cremation walked into a bar bragging about how this was the first funeral related to a person with HIV. Our friends were at the bar and when they told me about this, I could not believe it. I confronted the funeral director about it and he was apologetic.

44. Even before Keith died, our local council asked me to get rid of personal medical rubbish such as swabs, tissues and bandages into large yellow plastic bags that they provided. These bags remained outside our house for 3 weeks after Keith's death as no one would collect it. It was very distressing for me. This was a degrading behaviour for a council to make a huge issue about getting rid of medical waste and then not picking up. This was also very upsetting for Keith's family who came for his funeral.

45. There was a big stigma attached to those who had HIV at the time. Keith's health story became hot news where we lived. There were reports in the local Hitchin newspapers about him and other haemophiliacs in Hitchin who were infected. It first made the news in a newspaper called 'Comet' in 1985, just after Keith's diagnosis.
46. The reports named those that were infected. A friend from church was angry about this and wrote back to the newspaper giving a Christian perspective of this situation. I was scared that the media might adduce Keith's HIV to his lifestyle, such as being promiscuous or a drug user which he never was.
47. I also had the media knocking at my door asking if I wanted to share my story. We did not want people to think Keith had a risky lifestyle, and so we gave our friend permission to write an article in the local Comet newspaper about our Christian point of view.
48. The church was very supportive in this. We were well known at church and we had contact with 4 or 5 denominations. Keith used to tell people from these denominations about his health and people would pray for him.
49. However, Keith did have work-related effects. He started off lecturing in media studies at a local college. He was very chuffed and proud as this was his first job. He worked really hard to get this job. He managed for about a year and then he started to decline in sickness and was overwhelmingly tired. He started to pick up different illnesses.
50. I believe the tiredness was one of the first symptoms that he suffered and then it followed with other sicknesses such as the flu. We did not know in 1984 that the above symptoms were in relation to HIV. I recall that during his postgraduate course he had a really bad cold and took weeks off college. I believe this was as a result of the HIV.
51. The financial impact of Keith's HIV was dreadful for the both of us. We went from financially well off in 1984 to being on benefits. I used to work with



special needs children as well as mentally disabled people but I had to give it up to care for Keith.

## **Section 6. Treatment/care/support**

52. As mentioned above, the obstacles we faced as a result of Keith's infected status were at Lister hospital and the dentist where Keith was made to feel like a leper.

53. I do not believe that Keith was offered any counselling or psychological support. Keith had a number of church friends who were there for him so I do not know if counselling would have helped him.

54. I got shingles after Keith's death because of the stress it caused and after about 6 months, when the widow's allowance came to an end, I was totally wiped out and was very distraught. I could not sleep properly and some of these issues are still ongoing.

55. My GP recommended counselling and I remember breaking down in Dr Heelis' surgery. It felt like walking through a blackberry bush and being torn.

## **Section 7. Financial Assistance**

56. Keith did not receive any financial assistance from any of the Trust or Funds that were set up.

57. In or about the early 1990s after Keith's death, I received a lump sum payment from the Macfarlane Trust in the sum of £20,000. I recall I was asked to sign a waiver not to make a future claim. I had to sign it as I had no money.

58. I believe I heard about this fund at Addenbrooke's Hospital. The process of applying was straight forward.

59. I also received the Stage 1 payment of £20,000 from the Skipton Fund in or about 2010 or 2011.

60. I heard about the Skipton Fund from Keith's brother. I had no difficulties applying for the Skipton Fund and the application process was straight forward.

### **Section 8. Other Issues**

61. Even though I gave up my job in order to look after Keith, we were not eligible to receive carers' allowance. Keith's demeanor was always as a friendly person and when we had an interview, he came across as a pleasant and a healthy person. As a result, we were told that Keith had to be ill for 6 months to be eligible for this allowance. Keith was not able to get himself to the toilet and we were still turned down. Keith died after 3 months so that extra money would have helped us through this difficult time.

62. I wrote and published a book entitled 'Stigma: AIDS Widow's Story' on 9 June 1989. This book describes the journey of myself and Keith (named Kevin in the book) through this terrible time.

63. I wrote this book from a Christian point of view in order to help people understand that despite Keith's death, we could not let go of the miracles and the faith we had and how we got through it.

64. I have spoken to students in colleges and became one of the executive officers at the Stevenage drug line, which later became Stevenage HIV line.

65. I am upset that this scandal has been a cover up all these years and would like to see those who were responsible to be held liable.

### **Anonymity, disclosure and redaction**

66. 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.

67. 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 *18 February 2019.*