

Witness Name: G BUDGEN
Statement No: WITN3315001
Exhibits: WITN3315002-015
Dated: August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GLEN BUDGEN

I, Glen Budgen will say as follows:-

Section 1. Introduction

1. My name is Glen Budgen of GRO-C
Cornwall GRO-C. My date of birth is GRO-C 1961. I am married, I have two adopted sons aged 28 and 26 and a step daughter. I was the managing director of my own IT business and ran it from the year 2000 until 5 years ago. I am now semi-retired.
2. My father passed away in 2014 and my mother is in a care home with severe dementia. I have an older sister, Kim Knight and she has two children. Kim is also giving a statement to the Inquiry.
3. I make this statement in relation to my late brother, Victor Bugden, who was born on GRO-C 1963 and who passed away on 23 October 1998. As a result of receiving contaminated blood products, he was infected with HIV, Hepatitis A, Hepatitis B and Hepatitis C viruses.
4. This witness statement has been prepared without the benefit of access to my late brother's full medical records. I have been provided with some of my late

brother's medical records and the relevant entries are referred to in this statement.

Section 2. How infected

5. Victor was diagnosed with severe Haemophilia A with a 0% clotting factor from the age of ten months.
6. He was diagnosed at Colchester General Hospital and treated initially at the Edgeware General Hospital. From 1965 to 1976 he was under the care of the Great Ormond Street Hospital. In 1976 his care was transferred to the Royal Free Hospital (RF) in London where he was treated in The Katherine Dormandy Haemophilia Centre, under the care of Professor Christine Lee.
7. I have attached to this statement marked WITN3315002 an excerpt from Victor's medical records dated 10 September 1976 which sets out his medical and treatment history as at that date.
8. To treat his Haemophilia, when Victor was younger, he received Cryoprecipitate on a prophylaxis basis to prevent severe bleeds.
9. Later, in the 1970s and 1980s, he was given Factor VIII concentrate treatment at least three times a week. He started home treatment in his teens. Initially our mother administered the injections until he learnt how to inject himself. If he had a major bleed, he would need the injection every day.
10. I have attached to this statement marked WITN3315003 a copy of an extract from the National Haemophilia Database (NHD) which contains details of the treatments that were given to my brother (at pages 3-4).
11. In 1988 Victor took part in a trial for recombinant Factor VIII. He was the first volunteer in Europe. Victor knew it was experimental and by then he had been diagnosed with HIV so he knew it would not benefit him, however he signed up to the trial as he thought it would help others in the future.

12. Victor was infected with HIV as a result of being treated with Factor VIII.
13. Victor found out that he had HIV sometime in the early 1980s. I do not recall exactly what year it was that he found this out. I believe Victor would have been told of his infection by the Royal Free Hospital under whose care he was at the time.
14. I was in the Royal Navy at the time Victor became aware that he had contracted HIV. I was in the Navy from 1978 to 1986. I came home one day and my mother told me that Victor had contracted HIV from his Factor VIII treatments.
15. I have attached to this statement marked WITN3315004 the following documents from Victor's medical records:
- a. A form completed on 05 May 1998 which indicates that Victor was HIV positive from 1984;
 - b. Handwritten notes from 1984 and 1985 which suggest that AIDS was discussed with Victor on 15 May 1985. A note dated 3 October 1985 refers to the results of a test for AIDS.
16. The NHD records exhibited to this statement (WITN3315003) state that Victor tested positive for HIV on 15th July 1980. A letter dated 11 October 1990 to which I refer later on this statement and which is marked WITN3315010 states *"Mr Budgen is known to have been seropositive for anti-HIV since March 1981..."* My solicitor believes that these may relate to tests carried out on a stored sample.
17. Victor also contracted Hepatitis C but I do not know when he found this out. I was not aware while Victor was alive that he had Hepatitis C, but found this out after this death from my sister Kim.
18. A letter addressed to Victor from Royal Free Hospital 1990 which is attached to this statement marked WITN3315005 states that Victor first tested positive

for Hepatitis C on 16th January 1990. His medical records say that he still had Hepatitis C at the time of his death.

19. I have discovered from Victor's medical records that he also had Hepatitis A. In addition, he may also have had Hepatitis B.

20. HIV was already a big enough blow without these additional infections.

21. I refer to the following documents:

- a. a copy of the Post Mortem carried out after Victor's death which confirms at page 2 that my brother was infected with HIV, Hepatitis C and Hepatitis A viruses (exhibit WITN3315006);
- b. copies of Virology Reports from the Royal Free Hospital dated 1993 to 1997 (exhibit WITN3315007). These reports confirm that Victor had HIV, Hepatitis C and Hepatitis A infections. The report dated 25 July 1994 states that Victor tested positive for Hepatitis B Core Antibodies;
- c. an extract from a survey completed by the Great Ormond Street Hospital for the MRC Cryoprecipitate Working Party which records Victor as suffering from viral hepatitis in March 1970 (exhibit WITN3315008);
- d. a hospital admission record dated March/April 1970 which states that Victor was admitted with a diagnosis of hepatitis, and a letter to National Blood Transfusion Service dated 25 March 1970 which states that my brother had been treated with Cryoprecipitate and was suffering with symptoms of infective hepatitis (exhibit WITN3315009);
- e. a letter from the Royal Free Hospital dated 11 October 1990 which suggests that Victor had symptoms in 1988 which in retrospect were consistent with non-A non-B hepatitis (exhibit WITN3315010).

22. Victor was treated with Factor VIII as a child. I do not believe my parents were given adequate information on the risk of contracting infections from Factor VIII treatment. Our mother now suffers from severe dementia and our father passed away in 2014. I have attached to this statement marked Exhibit WITN3315011, a copy of a newspaper article from 1996 in which my mother

is quoted as saying that they were told that Victor was at risk of contracting hepatitis. It is not clear when they were told of this risk. They were not told that there was a risk of HIV.

23. When Victor was diagnosed with HIV, I do not believe that adequate information was provided to help him manage or cope with his infections.

24. No one ever told us how HIV was transmitted and there was a lot of fear at that time that HIV could be contracted by hugging or kissing. We had to seek facts from our local GP about HIV and the information we were able to get was unfortunately inadequate. In those days, HIV meant AIDS, and AIDS was such an unknown quantity that you did not know if you were going to catch it or how to manage it. We all thought it could be transmitted easily. The lack of information and fear unfortunately made Victor very isolated. He was fearful about passing HIV to us through contact and so he held back from his family. We were also fearful and this made us overly cautious around him. I remember being paranoid that little things could put me at risk, such as rubbing suntan lotion on him or giving him a hug.

Section 3. Other Infections

25. As far as I know, Victor was not infected with any infections other than those referred to in this statement.

Section 4. Consent

26. I do not know if my brother was tested or treated without his knowledge or consent. Most of his Haemophilia treatment was administered as a necessity. Without it, Victor would have died so I do not know if the issue of consent would have been discussed with him or my parents.

27. Victor volunteered himself for any research trials that may have helped others in the future. In 1988 he took part in a trial for recombinant Factor VIII. I refer

to Exhibit WITN3315010 and to Exhibit WITN3315011. I also attach a letter from the Royal Free to my brother's employer dated 20th July 1989 in relation to his involvement in the trial, marked exhibit WITN3315012.

28. I refer also to exhibit WITN3315003 which suggests that Victor was part of Dr Craske's research work in 1976.

Section 5. Impact of the Infection

29. Victor never spoke much about his HIV infection. He was very young when he found out that he had HIV and I know that he was worried about his future, however he tried not to show this outwardly and he kept a lot to himself. He became very withdrawn in relation to his infection – he would not talk about his infection or his health. He adopted an "I live for the day" attitude. He did not want to upset the family and this was his way of dealing with things.

30. Victor was a very caring person and would always think of others before himself. This was shown by him volunteering to be a guinea pig for any new treatments.

31. Although Victor had a disabled badge he would refuse to use disabled car parking "as other people needed it more than him". This was the type of person he was and because of his kind nature, over two hundred people attended Victor's funeral.

32. After I left the Royal Navy in 1986, I lived in Bolton Lancashire. I saw Victor around 8 times every year. Sometimes I visited him and sometimes he visited me.

33. I am not aware of all the details of Victor's treatment but I knew he was taking some drugs for HIV. He was under the care of The Katherine Dormandy Haemophilia Centre, at the RF and this is where he received treatment for HIV. I was not aware of Victor's Hepatitis C infection while he was alive, but his medical records say that he was treated with Interferon from November 1991 to May 1992.

34. I do not know if he faced any difficulties or obstacles in accessing such treatment.

35. Victor was diagnosed with AIDs around 1994 or 1995. I refer to a letter from the Royal Free dated 10 January 1995 which is attached to this statement marked WITN3315013

36. I have attached to this statement marked Exhibit WITN3315014 the following letters from the Royal Free:

- a. letter dated 30 March 1993 relating to symptoms of HIV and stigma faced by Victor;
- b. letter dated 20 May 1994 relation to treatment he received for HIV and symptoms he experienced;
- c. letter dated 9 November 1994 relating to HIV related seborrheic dermatitis suffered by Victor;
- d. review letters dated 22 March 1995, 7 February 1996, 14 November 1997, 30 December 1997 and 19 February 1998 which contain details of Victor's infections and his treatment for HIV and Hepatitis C;
- e. letter dated 21 April 1998 confirming diarrhoea and rapid weight loss as a result of HIV.

37. Victor suffered from very severe skin problems which were attributed by the hospital to his HIV infection. From October 1997 he suffered from severe diarrhoea and rapid weight loss which were also thought to be related to his HIV infection.

38. Towards the end of his life Victor's health deteriorated drastically. Every time I came home I could see a difference in him - he was worse than the time before. He was always catching colds and generally feeling very unwell. As a result, a large part of his time was spent in and out of hospital.

39. In the last two years of his life, he experienced severe weight loss. He went from being a big chunky 5 ft 11 man to all skin and bones, a sliver of himself.

At a guess I would say he went from weighing around 14 stones to weighing around 9 stones. In pictures of him during that time, he looked like a skeleton.

40. I visited Victor in hospital in 1998 shortly before he died. When I arrived at the hospital, he was on a drip wearing an oxygen mask. He was also wired to machines and his eyes were sunken. He was so weak and couldn't really speak much. All he could do was nod his head.

41. My parents were still very hopeful that he would fight the infection off. We knew he was pretty bad but he had been in poor health before this time and he had managed to overcome the situation then.

42. My mother told me not to visit Victor daily because she did not want him to think that something was seriously wrong. I went home expecting that he would get better. Victor died two days later. This was gutting for me. I wish I hadn't listened to my mother and I really regret my decision to go home because I wasn't able to make it back in time to see him alive. I couldn't say good bye to my brother. I should have been with my brother when he died, but I wasn't.

43. Victor died on the 23rd October 1998 of Pneumocystis Pneumonia caused by his HIV infection and from AIDS. I refer to the Post Mortem (exhibit WITN3315006). He was 35 years old.

44. Victor was very young when he contracted HIV and this deterred him from pursuing any relationships. He did not want to pass the infection on to anybody so he never had a girlfriend or a family of his own. He was denied this opportunity. He filled the void in his life by spending time with his family. Victor was a very loving brother. He would often come away with my wife and I on holidays. He also frequently went away with my sister and her family.

45. Victor was always going round to my sister's home and visiting her children. As Victor had decided he was never going to have his own children, my sister's children practically became his children and he loved spending time with them.

46. I didn't see Victor as often because I lived further away. Whenever he visited my home, or I visited him, he loved spending time with my children, whom I had adopted a couple of years prior to Victor's death. Victor played with all of his nieces and nephews and he would spoil them rotten.
47. I was very close to my brother. When I found out he had HIV by no fault of his own I was very angry that such a thing could have happened. He already had severe haemophilia, and on top of this, to be given HIV was unbelievable.
48. Victor lost out on physical touch from his family. He must have felt very isolated. We had always been close before his diagnosis.
49. Growing up as young boys Victor and I were quite physical with each other, there was lots of rough and tumble between us and we would push each other around. That all changed after his HIV diagnosis. It sounds awful, but because we never fully understood the risk of transmission, we were scared of being too close to one another.
50. I was in the Navy and living away from home when he was diagnosed. However when I did come home things were different. Although we remained close in other ways, there was a physical distance that was not there before, things were not the same. We no longer touched or hugged freely like we had done before. There was fear on our side and there was fear on Victor's side and so we all held back. In those days HIV was the same as AIDs and we all didn't know how to deal with it. We did not know if we would catch it by touching him and this affected our family. It was only in the 1990s that we knew that HIV was not as easily spread as we had previously believed.
51. Victor's HIV was not talked about much outside of the family due to the stigma of AIDS at the time. Even within the family we avoided talking about his infection. I never had any real in depth conversations with Victor about his infection.
52. I recall a brief conversation I had with Victor. He was on holiday with my wife and I. This would probably have been in the mid to late 1980s. I was unsure

about whether I could rub suntan lotion on his back and Victor explained to me that you do not get HIV by touching people.

53. I refer to a letter from the Royal Free dated 20th March 1993 (exhibit WITN3315014) which relates to pressures that Victor faced at work due to stigma.

54. The death of Victor hit our family hard as he died so young and missed out on so much. It devastated my parents. My father never really got over Victor's death. He died in August 2014. My mother continued to support the Katherine Dormandy Trust and attended the annual remembrance ceremony at St Bartholomew Church in London until her dementia prevented that. My sister and I also attended the remembrance service when work permitted. My mother is now in a nursing home with severe dementia and has a life expectancy of six months.

55. Victor was an incredibly fun uncle and all his nieces and nephews loved him dearly. He was very close to my sister's children. My sister lived closer to Victor than I did and her family were his second family, her children were like his surrogate children, they all went on holiday together. Victor's death, when our niece and nephew were 16 and 14, affected them particularly badly given their ages and their closeness to Victor. Unlike my children who were aged 2 and 4 at the time, my niece and nephew were old enough to mourn the loss of their uncle.

56. When Victor went into hospital for the final time, my niece and nephew believed that Victor was going into hospital for some tests. They had no idea that he would not make it out alive and they were both devastated to lose him.

57. Victor had an excellent work ethic. He worked in the post room of a construction company, Laings plc, from when he left school until two weeks prior to his death. His workplace was aware of Victor's illness and gave him the job knowing that he may need to take time off. Victor was very loyal to his employer and tried as much as possible not to be off work. Even with his

haemophilia, after a major bleed, as soon as he was treated he would return to work, sometimes going to work straight after receiving treatment at hospital. He would drag himself out of bed as work kept him going and gave him purpose. In his final two years, Victor had to take more time off work, and not being able to work didn't help Victor at all.

Section 6. Treatment/care/support

58.No counselling was ever offered to the family. My parents, sister, niece, nephew and I were left to get on with things and cope with Victor's premature death.

59.After Victor passed away, no bereavement support was offered to my family.

60.In 1999, my parents received a letter from the MacFarlane Trust admitted that there had been a lack of bereavement support and that there would be research conducted in this area. A copy of this letter is exhibited to this statement marked Exhibit WITN3315015)

Section 7. Financial Assistance

61.I was told by my parents that the only payment made to Victor was the one off government payment of approximately £20,000. I do not know when this was received or which organisation made the pay-out.

62.I believe that this money was given to pay my brother off and make him go away without asking any further questions.

63.As far as I am aware no other payment has ever been made to my parents. No payment has ever been made to my sister or me.

Section 8. Other Issues

64. Finding out about Victor's infection made me feel very angry. My brother was already dealing with severe haemophilia and now he had to deal with HIV too.
65. My family and I questioned how this had happened. Where did the blood come from that was used to treat Victor?
66. My mother gave 100 pints of blood for Factor VIII. I gave blood regularly while I was in the Royal Navy until I became Air Crew and could not longer do so. Yet Victor was treated with infected blood.
67. My family and I believed that Victor was treated with blood from the UK but we have heard that it was cheaper to get blood from the USA. It is clear from the NHD records that Victor was treated with commercial products from the outset (Exhibit WITN3315003).
68. I do not understand why hospitals were not sterilising or heat treating the blood products until after people were infected with HIV.
69. I believe that the contaminated blood issue has been handled very badly. My brother didn't have a life, he was denied his own family, and we have been denied nephews and nieces. The toll on the victims and their families is immense. Not only did they infect people, but they omitted to offer any help or assistance. The hospitals gave no information to patients and in doing so, have isolated them. Victims have been treated like numbers, not like humans. Victor was not a number. He was a son, brother and friend.
70. My brother was a selfless, light person who touched the hearts of so many people. No matter how stressful it was for him, he never thought twice about volunteering himself for trials or research. He has been killed and I no longer have a brother.
71. My father passed away and my mother has severe dementia. They were both heavily involved in the Haemophilia Society and the RF decided to honour the

memory of my brother by naming a new research fellowship after him. It is now just me and my sister and I would like to continue this fight on behalf of Victor and get him the recognition he deserves. It would be nice to get some answers before the two of us die too.

72. Somebody should be held responsible for what happened and how it was dealt with and they should promise that nothing like this will ever happen again.

Anonymity

73. I do not wish to remain anonymous and I want 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

29/8/19