

Witness Name: Barbara Campion

Statement No: WITN6890001

Exhibits: WITN6890002-3

Dated: December 2021

FIRST WRITTEN STATEMENT OF BARBARA CAMPION

I, Barbara Campion, will say as follows:-

Section 1. Introduction

1. My full name is Barbara May Campion. I was born on GRO-C 1944 and I live at GRO-C
2. My son, Simon John Campion (born on GRO-C 1969), was co-infected with the Human Immunodeficiency Virus (HIV), the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died on 28th July 1996, aged 27.
3. This witness statement has been prepared without the benefit of access to my son's medical records. I was given to understand that they were destroyed, through a fire or flood or otherwise (we have been given conflicting information).

4. My daughter and son in law have both provided Witness Statements to the Inquiry (WITN1554001 and WITN1555001). Since doing so, my son in law has uncovered a limited number of medical records via the Leicester Royal Infirmary (LRI) where Simon was last hospitalised, and some additional papers have been found and provided by the National Haemophilia Database.

Section 2. How Affected

5. Simon had severe Haemophilia A and was treated at the Derbyshire Royal Infirmary (DRI).
6. Simon was treated with a variety of blood products to include Alpha FVIII (Profilate), BPLF VIII, NHS Factor VIII, Replanate (BPL), Profilate, Factorate, Oxford VIII, Cutter FVIII (CO8), Cryoprecipitate (Kryobulin) and Koate.
7. I refer to Exhibit WITN6890002 being a copy of the National Haemophiliac Database (NHD) records referred to at paragraph 4 above. The information includes the date of Simon's first HIV positive test result being 5th February 1985. The medical records received via the LRI at Exhibit WITN6890003 include a letter confirming that Simon would have become infected with HIV as a result of receiving contaminated blood products prior to 1985 (presumably some time in 1984, if not before). We were not told that Simon had been infected with HIV until sometime towards the end of 1985/beginning of 1986.
8. We had no idea that Simon was also co-infected with HBV and HCV. We were never informed of it by any of Simon's clinicians. It was only at a case conference when Simon entered the Sue Ryder Hospice in the days before his death that hepatitis was ever even mentioned to us. The NHD record gives an approximate date for the onset of HCV (to include previously raised/abnormal LFTs) as 21st November 1986, 10 years before Simon's death. The notes are

clearly indicative that Simon had a very serious infection causing swelling of his liver and spleen.

9. Referring again to the documents at Exhibit WITN6890003 (only received by us on 8th December 2018), it is clear that Simon's Consultants were fully aware that Simon was co-infected with HBV and HCV in 1996. It would be as long as 22 years before we uncovered clinical evidence of the hepatitis diagnosis. One such document even states that 'If this patient needs dental treatment, he should tell his dentist'. The information wasn't relayed to us and Simon was completely reliant on us for his care. Doctors at the DRI offered their condolences to us when Simon died yet for all these years later to include when we tried asking for Simon's notes, we were never informed of the true circumstances surrounding his death.

Section 3. Other Infections

10. We have uncovered notes referring to Simon having been placed at risk of vCJD.
11. Referring to paragraph 9 above, Simon's HCV infection was not acknowledged, and Simon was failed in being treated appropriately. We were told that the chronic diarrhoea Simon suffered with for so long was due to his poor tolerance of AZT. Because of that Simon stopped taking AZT for some long period of time before his death but the diarrhoea never cleared up.

12. The wider family were placed at risk through ignorance of the HCV issue. My

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13. Referring again to Exhibit WITN689002 (and Dr **GRO-D**'s signed record dated 24th October 1994), we were not informed that Simon's HIV had advanced and was classified as AIDS as long as two years prior to his death.

Section 4. Consent

14. Given what we have uncovered, we, as a family, are now very concerned that Simon might have been treated and tested deliberately/for the purposes of research.

Section 5. Impact of the Infection

15. Haemophilia runs through our family. My grandmother and great grandmother lost several brothers and my cousin lost her son to it. When Simon's cord was cut at his birth, it bled profusely. My husband, Michael (Mick) and I were sent to take Simon to see a Dr **GRO-D** at the Derbyshire Children's Hospital when he was six months old to confirm the diagnosis. Dr **GRO-D** said to Mick of me 'Did you know what you were taking on when you married her?'
16. Simon was hospitalised many times as a baby with bleeds to the knees or arms or his mouth. He was given injections into his head and was at some point transfused but the dates escape me. Typically, Simon was hospitalised for two or three days sometimes a week. From the age of around 5 years old, Simon transferred to the Haemophilia Centre at the DRI under the care of Dr Winfield. When Simon was 8 or 9 years old, Mick went to learn how to inject him with Factor VIII (FVIII) concentrate (home treated from 1977).
17. There was no warning as to risk of infection beforehand. FVIII concentrate was thought of as a better treatment. Once Mick was able to inject Simon then it

meant the family could go on holiday for the first time because as long as the FVIII treatment was refrigerated then travel was possible. Hospital appointments were still regularly required for check-ups.

18. Simon's GP at this point was Dr Steadman. He was treated for asthma and measles. Simon was provided with crutches due to bleeds and wore a splint for some weeks. At this time, he was treated by Ashby Medical Centre on North Street.
19. Simon's school life was difficult as he was never able to go out and play at school. Arrangements were made for Simon and his sister Louise to go to school late and leave early in order to avoid other children causing injury. Simon did have a couple of school friends who looked out for him. Some of the teachers were really good to Simon and looked after him with care at Burton Road Junior School. Simon later attended Ivanhoe Senior School.
20. Simon fell behind in School and had to take work home in the holidays to try and catch up. He was not allowed to do PE in school and could not play sports. Instead he would concentrate on things such as woodwork, handicrafts and baking. When Simon was 16 years old, we (the family) started to hear reference to 'a gay disease', and then comments were made suggesting people that had had blood transfusions were being infected with mystery illnesses. Shortly after that, we took a phone call from Dr [GRO-D] who was the new Haematology Doctor at the DRI. [GRO-C] Louise and I were asked to attend the hospital on a Saturday to have blood tests. On a previously occasion, [GRO-C] had been asked to provide a blood sample. [GRO-C] Louise and I were subsequently told that our test results were clear, but Simon was required to go for further testing. His test came back that he was HIV positive.

21. We were invited to attend a consultation and we were served tea and cake.

There were many academics and doctors present. Louise and I felt very uneasy as we were constantly talked over by the academics as if we were not there. A dentist at the session remarked that he would not treat anyone with HIV. From the time of Simons diagnosis there was very little support as no one really seemed to know what was going on. There was also what can only be described as a lot of attitude surrounding the diagnosis. I recall a lady mentioning to the team that she had told her employer that her son had HIV and she was sacked. Mick and I were concerned for our own jobs and were told to go away get on with their lives and to keep quiet. Simon was hospitalised shortly afterwards. I recall that Dunblane happened at this time and that lumbar punctures were taken but explanations were never given as to why.

22. When Simon left school in May 1988, he went to work for Nevastrone Products in Coalville and, around this time, my brother [GRO-C]

[GRO-C] Simon learned to inject himself and Louise diligently kept a diary of all the FVIII treatment that was administered and the reason why it was administered with batch numbers (and she still holds this diary). Because of press scare mongering and misinformation and fear, we became very insular as a family, keeping things very private and never saying anything regarding Simons condition for fear of reprisal. Prejudice was always a regular issue (and I was even accused of battery because of Simon's bruising). We were always very afraid of reprisals. From this point in Simon's treatment he was treated differently when hospitalised and kept in isolation. Meals were brought to him separately and people would not want to touch his dirty pots or remove them. Simon commented that he felt like he had Leprosy. I did complain to the haemophilia department asking why he was treated that way when we were clearly told that HIV cannot be caught this way. The hospital brushed away the complaint with a blasé apology saying sorry I felt that way. Simon's GP at this time was Dr Hoffman. He was wonderful with Simon and treated him with respect and dignity. Simon's dentist was Dr [GRO-D] of the Nottingham Road

Dental Practice. If Simon needed treatment, he was always sent to hospital with the comment that it would be safer for him.

23. Craig (my son in law) and Louise started dating in 1988, whilst out in the car and listening to Radio 1 there was talk of HIV and AIDS on the radio. Louise asked Craig to pull over and explained about Simon's HIV. Louise thought this would probably be the end of their relationship but was relieved to have someone else to talk to. Louise held a job as a nanny at a hotel never telling her employer of Simon's condition out of fear of reprisals. At this time Simon was being bullied because some people knew of his haemophilia and he suspected they had guessed his positive HIV status. He was physically attacked at a bus shelter. Luckily a work colleague saw this and pulled three lads off of Simon. In early 1987 Simon started dating a girl from work. Obviously, Simon could not have a sexual relationship and the couple went out until 1990. His girlfriend would visit Simon most weekends. One weekend her mum phoned up wanted to know where she was and was very rude. It seemed that her parents were not happy about something. We believe that Simon told her about his condition, and she must have confided in her parents. Within a week issues started to occur at Simon workplace and his boss was constantly funny with him, accusing him of poor workmanship. Simon was always consistent in his work and photographed his work. We couldn't see any reason for a change in his standard and we think that his girlfriend's parents had told Nevastrone products of his condition. Simon was sacked on May 4th 1990. He did consider starting legal proceedings using a firm of solicitors in Hucknall. Simon was advised not to pursue a complaint as it would probably go badly for him with his condition becoming public.

24. Simon's Uncle owned a farm in Cornwall and offered Simon work as a farm labourer in August 1990. Mick by then was not coping well with Simon's condition.

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GRO-C	Mick was made redundant from the National Coal Board
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GRO-C	Simon worked in Cornwall until November 1990, when he came home and this was when his health started to deteriorate, initially with a bout of shingles. Simon started to become far quieter, and more withdrawn,
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25. In June 1991 Simon received a payment of £23,500 as so-called compensation but under threat to keep quiet and sign a disclosure that he would not ask for further compensation. Simon was granted Disability Living Allowance and Mick received Carers Allowance. By 1992 Simon was regularly getting ill and contracted shingles again. Simon was started on a course of AZT which he found toxic, making him feel sick with regular stomach upset and generally feeling lousy. He coped reasonably well until May 1993, but he lost a lot of weight. It was of course only shortly before Simon death that we discovered he also had HCV and we now wonder whether his symptoms were attributable to that.

26. Simon quickly regressed from reasonable physical health to walking with a stick and then a walking frame. By mid-1993 we were struggling to get a wheelchair from local authorities, but the Red Cross stepped in and provided one. Local authorities were arguing who should pay for his care (Leicester vs Derbyshire). Around this time Simon started to refuse to take his AZT because of the believed toxicity of it. He was permanently sitting on a commode as he was rapidly losing bowel control. A bed guard was installed, and a stair lift in order to enable Simon to get upstairs and works were planned to create a wet room downstairs. Craig contacted to Terrance Higgins Trust to find out about possible support and they kindly put us in touch with Leicester Aids Support (LAS) and we received support from thereon with help from Jenny Deakin. Jenny was responsible for signposting us for support and a district nurse started

to visit from early 1996. Simon's spine became infected and the cord damage was so complete that he became confined to a wheelchair as a paraplegic. Simon lost his mental dexterity and was constantly bleeding from his bottom, the size of the bed sores he had you could put your fist in. The bathroom of the house was converted to accommodate Simon, but he never had the chance to use it as he was admitted to LRI because Jenny was not happy with the treatment he had received at Derby. LRI treated Simon again in a single room and he was left dirty and unwashed and his clothes left on the floor. On consultation with the hospital they basically said there was no hope for Simon and to take him home. Simon was admitted to Sue Ryder home at Staunton Harold where he died 10 days later. On speaking to an undertaker prior to Simon's death we were told he would have to have a closed casket. Jenny advised us that we may find a friendly undertaker that would treat him with more dignity. The undertakers we went with in Ashby agreed to an open casket as long as he was previously dressed - although he had to be placed in a body bag because this was left open for viewing. Although sympathetic to our wishes we still felt he was prejudiced in death. Craig instigated a firm of solicitors to take care of Simon's estate, the solicitor asking Craig if he was Simon's gay partner. Even after Simon's death the prejudice continued, and we were unable to be honest as to how Simon had died.

27. A synopsis of the impact of the infections on Simon's health are as follows: recurrent infections; chronic infections; bio-lateral lower limb mobility and wasting; low muscle power; class knife rigidity; fixed flexion deformity; constant diarrhoea; loss of bladder control; upper motor paresis; constant hemoarthrosis and poor mobility and epistaxis and encephalitis.

28. The impact of the infections on Simon's mental health was really sad and upsetting for us as Simon was generally a happy and outgoing positive person. However, he became angry and sometimes showed his anger. He tried to stay positive for others but became quiet and withdrawn and did not want to discuss his health.

Section 6. Treatment/care/support

29. There was very little care and support for any of us from the outset.

Section 7. Financial Assistance

30. I refer to paragraph 25 above.

Anonymity

31. I do not seek anonymity and I understand that this Statement will be disclosed for publication to the Inquiry.

Statement of Truth

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

Signed.

GRO-C

Dated 15/1/2022