

Witness Name: ELIZABETH GAIL HOOPER

Statement No: WITN3514001

Exhibits: 0

Dated: JULY 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ELIZABETH GAIL HOOPER

I, ELIZABETH GAIL HOOPER, will say as follows:-

Section 1. Introduction

1. My name is Elizabeth Gail Hooper. I was born on [GRO-C] 1965 and I live at [GRO-C] Warwickshire [GRO-C]. I am a widow having lost two husbands. Jeremy was my first love and Paul was my soulmate.
2. My husband, Jeremy Foyle (born on [GRO-C] 1965) was co-infected with the Hepatitis B Virus (HBV) and the Hepatitis C Virus (HCV) through contaminated blood products. He died due to an internal gastrointestinal haemorrhage on 9th December 2008, aged 43.
3. My second husband, Paul Hooper (born on [GRO-C] 1964) was co-infected with HBV, HCV and the Human Immunodeficiency Virus (HIV) through contaminated blood products. He died due to a cerebrovascular accident on 1st December 2017, aged 54.

4. This witness statement has been prepared without the benefit of access to Jeremy and Paul's medical records.

Section 2. How Affected

Jeremy

5. Jeremy had severe Haemophilia B. His diagnosis arrived relatively late, at the age of nine, after a series of bleeds left him on a plasma drip with both legs in traction. There was no known history of haemophilia in his family. GRO-C
GRO-C
GRO- Dr Matthews told us that the gene can skip up to 12 generations.
6. Jeremy was treated at the Oxford Haemophilia Centre at the Churchill Hospital under the care of Dr Matthews and Dr Rizza. Jeremy moved to Kington with his family when he was 13 years old to be closer to the Centre. Jeremy and I went to the same school and we married in 1987.
7. Jeremy was treated with Factor IX (FIX) concentrate. If he had a particularly bad bleed he needed to use two large syringes and I would help change them over. No advice was provided to Jeremy (or his parents) about the risk of being exposed to infection from FIX. It was hailed as a wonder drug.
8. Occasionally there would be reports on the evening news involving the blood of haemophiliacs being contaminated with infectious diseases but generally Jeremy felt fine and mostly didn't take much notice. He trusted his doctors. When all the horrible gravestone adverts started on the television, Jeremy asked Dr Matthews about HIV and questioned if he was at risk. Dr Matthews said they had tested him and he was clear and that he was not aware of anyone with Haemophilia B having contracted it. He also said that the FIX concentrate was 'extra heat treated' and Jeremy was reassured by that. Jeremy was living a normal life, a happy normal life, doing what he wanted, when he wanted. In 1993 our son Lewis was born.

9. In 1995 or 1996, Jeremy answered a call from Dr Matthews telling him to "come in and bring Liz". I did occasionally accompany Jeremy to his appointments when I wasn't at work. I arranged a babysitter for Lewis and went to the Centre with Jeremy.
10. Dr Matthews explained to Jeremy that he had HCV and that he had had it for approximately 10 years. Dr Matthews said that the reason they called him in was to explain that Jeremy's liver had started to show that it was declining so they had to tell him. They wanted to do a liver biopsy and to put him forward to try a new treatment in the hope that they would be able to kill the virus. If the treatment didn't work a liver transplant was the only alternative.
11. Jeremy asked why it was that he had not been told for a full 10 years. Dr Matthew said that they had been closely monitoring Jeremy's liver and that there had been no reason to be concerned. Jeremy said "I cannot believe you just said that." Dr Matthews explained that HCV was formerly known as 'Non-A Non-B' and it didn't have an official name up until that point. Jeremy said "and I'm sure you spent hundreds of thousands of pounds deliberating before you came up with the name Hepatitis C" dripping with sarcasm.
12. Jeremy asked about the risk of passing the virus on. Dr Matthews said "yes that's why we wanted Liz to come in as the virus has the potential to live in the seminal fluid. She needs to be tested too". Jeremy said "You bastards. You knew when Liz was pregnant and we now have a child and you didn't bother to tell us at any time. Jeremy was livid. He was fuming. The language was foul. He was furious because he feared he had passed the virus on to me and our son. Jeremy then said "Come on. Let's go. The damage is done."
13. I was in shock and in a state of confusion. I would say that we were in the meeting for approximately half an hour, possibly 45 minutes. It was not very long really given the magnitude of what Dr Matthews was saying. It was a very emotional meeting and Jeremy was beyond angry. He was beyond angry and spitting fire as we left. He got up and I followed him out.

14. I was shell shocked. As a mother my overriding thoughts were for my baby. I went back within a couple of days for the test and was given a negative result. It was an anxious wait but it meant our son was in the clear too.

Paul

15. Paul had severe Haemophilia A. He was diagnosed at birth. GRO-C
GRO-C Paul attended a main-stream school but was taken out because of issues with bleeds. He was then sent to a school for children with physical disabilities in the Birmingham area.
16. Paul was treated at the Birmingham Haemophilia Centre at the Old Queen Elizabeth Hospital initially under the care of Dr Hill. Dr Wilde took over from Dr Hill. All the time I knew Paul, he was under the care of Dr Wilde.
17. Paul was treated with Factor VIII (FVIII) concentrate. Before I knew him, I know he was treated with cryoprecipitate. Paul was not pre-warned of any risk associated with FVIII blood products.
18. Paul told me when I met him in 2009 that he had HIV and HCV and that he had been infected for 25 years but he was not told for a number of years.

Section 3. Other Infections

19. Jeremy had been exposed to HBV. I know that he had the virus because Lewis and I were vaccinated against HVA and HBV prior to going on a family holiday to Egypt. Jeremy was told that there was no need as he already had the HBV antibodies.
20. Paul was also infected with HBV. Moreover, Paul received a letter notifying him that he was at risk of vCJD.

Section 4. Consent

21. Jeremy did not know he had been tested for HCV. Moreover, he was not told that he was tested for HIV until he questioned the risk with Dr Matthews and Dr Matthews told him he had tested HIV negative.
22. Paul did not know he had been tested for HIV and HCV either.

Section 5. Impact of the Infection

23. I never meant to fall in love with two haemophiliacs any more than I intended to be widowed twice. Jeremy and Paul were very different characters. Jeremy was loud, gregarious and larger than life. Paul was gentle, quiet and dry witted.

Jeremy

24. The Headmaster announced that Jeremy was joining the school at an assembly in my third year of secondary school. He said that a pupil would soon be joining us and that he had a disease that meant his blood didn't clot, so no-one was to pick on him and no-one was to fight with him. I was intrigued but singularly unimpressed when Jeremy arrived. There was nothing mysterious or delicate about Jeremy. He was a sturdy, confident character with a cocky, Jack-the-lad manner. Moreover, Jeremy seemed to go out of his way to disregard his condition. He got into fights and joined a boxing club.
25. After taking O-levels, I stayed on at school while Jeremy dropped out. I didn't see him other than occasionally just around the village sporting a punk style haircut.
26. In 1982, when I was 16 years old, I went to a school end-of-year party in the village hall. Jeremy gate-crashed and I was astonished at how he'd changed. He'd shot up in height and the punk haircut and the puppy fat had gone. He

was dressed like the singer of some post-punk band: black Doc Marten boots, narrow black jeans, a grey shirt and a vintage German military jacket. He'd become a proper man and there was an instant attraction between us and five years later we were married.

27. Jeremy rose from being a counter assistant at a builders' merchant to a series of roles as a sales rep and, eventually, as a company sales and marketing director. He was very driven and we were very happy. We owned our own detached home, had nice cars in the driveway and enjoyed holidays abroad. We had a wide circle of friends, and Jeremy would hold court at barbecues and parties. If you were in a crowded room, you always knew Jeremy was there. He was always the life and soul of the party. We had a very tight loving relationship and our son Lewis born in 1993 was the icing on our cake.
28. Jeremy endured heavy bleeds that left him in great pain and restricted his mobility. He went on to develop joint arthritis. Jeremy was reluctant to take part in the HCV treatment trial and we discussed it a lot between us. He did not have treatment until Lewis was about 11 years old. He had developed liver scarring and was feeling tired and lethargic. He had six months of treatment of Ribavirin tablets and injections of Interferon and it was horrific.
29. Jeremy had violent headaches. He would shut himself away from Lewis and me and would scream at me if Lewis made noise. The drugs also made him nauseous, he rarely ate, he was unable to sleep and he became aggressive and short-tempered. It was probably the closest he and I ever came to being divorced.
30. Jeremy spoke to the Haemophilia Centre about the headaches. They said they couldn't give him anything so he should take paracetamol. He popped them like they were smarties. One day he was reading the leaflet on the clearing treatment and in big bold letters it said 'paracetamol is not to be taken with this medication'. He had been taking it for weeks. It was clear the

department supplying the HCV treatment were not communicating with the Haemophilia department.

31. Jeremy was under a lot of pressure at work as Sales Manager and we relied on the income. He continued to try to hold down his job during the clearing treatment and, when he was not shut away from us, he communicated in grunts and shouts and was very abusive. He ended up on antidepressants and stayed on them after the clearing treatment. He was never himself again. He never bounced back to being the man he had been.
32. At the end of the course of treatment Jeremy was told that he still had the virus. It was six months of total hell for no reason. Jeremy couldn't face going back on the medication again. He realised his own mortality. He said he would rather die than do it again because of the way he had treated us. We resolved to struggle on. Over time Jeremy began getting stomach pains and polyps was bandied about by the doctors as a possible cause. An endoscopy didn't reveal anything untoward.
33. The day of 7th December 2008 started like any other. We had breakfast. Lewis (then 15 years old) went to school and I went to my part time job. I was in a meeting just before lunch when a colleague interrupted us. Jeremy (working from home that day) had been trying to get hold of me and had also left me voicemail messages begging me to come home immediately. I raced home and shouted Jeremy's name as I stepped through the front door. No one answered. I went upstairs and opened the bathroom door to be met by a horrific sight. Jeremy had been vomiting blood and the bathroom was covered in it.
34. Jeremy was lying on the bed, ashen-faced and barely conscious. He was rushed to hospital and I was told that an endoscopy was booked for the next day. Oddly, they could not apparently perform the endoscopy that same day because they needed to find the equipment they used last time (because Jeremy was a haemophiliac with HCV).

35. On the way to have the endoscopy next morning, Jeremy said "Right, I'm going to get this done and then I'm going home and I want to have a hot bath and a big cup of tea with sugar". He didn't normally take sugar, only on special occasions, as a treat. Those were the last words he ever said to me.
36. The endoscopy was put down his throat but it didn't get very far before an internal bleed erupted. He then had a cardiac arrest. The medical staff resuscitated him and rushed him into surgery. I was told to contact the family. One of Jeremy's sisters lived in Yorkshire and she drove to the hospital. I was so worried about her driving that distance knowing that her brother was likely to die. I was relieved to see her when she arrived.
37. A doctor summoned me to update me and I knew from his expression what he was going to say. There was nothing they could do. I still feel ashamed of myself. I remember screaming, getting on the floor in front of the doctor and begging him to take my blood and give it to Jeremy. The doctor told me it was too late for that. When I calmed down, he said that Jeremy's body had been saturated with whole blood and he was rejecting it.
38. The doctor asked if I wanted to see Jeremy. I did, but I later deeply regretted going into the operating theatre. There was blood everywhere. It was coming out of his mouth and out of his nose and even the corners of his eyes. His body was just rejecting everything. I couldn't stay with him. It's a memory that I've got etched in my mind and it was just like something from a horror film. He was a big man and there he was with blood everywhere. It was just awful. I gave him a kiss and told him I loved him. I then turned my back and walked away. I was so glad that Lewis had opted not to see his father. I said to Lewis "come on we're going home". There was nothing I could do for Jeremy. It would have served no purpose sitting there with him. Jeremy died just before midnight. I had no idea that Jeremy, who was never a big drinker, had developed cirrhosis of the liver. On his death certificate, HCV was listed as a cause.

39. Jeremy carried on working until the day he died. We had no financial support and were not aware of any except Disability Living Allowance. We only found out about that by chance because GRO-C and the consultant (who had nothing to do with haemophilia) mentioned that he thought Jeremy should be entitled to it. Jeremy was told by that consultant to get in touch with his Centre as he was probably entitled to the maximum.
40. Before I could face up to the loss of the man I had loved for 26 years and confront his horrific death, I had to go into survival mode. I didn't know where to begin. Jeremy had always looked after our finances. He had been on a good wage, and my part-time salary wasn't enough to cover the mortgage. I was eligible for £25,000 from the Skipton Fund but it was a drop in the ocean.
41. As part of the mortgage we were allowed a 3 month mortgage holiday. I rang and explained that Jeremy had passed away and I asked for the mortgage holiday. I had to sell the house by the March because then I would have to start paying money I did not have. I had no income except my monthly salary and a modest widow's pension of £179 month paid into by Jeremy. I downsized to a modest two-bedroom house. It was a wrench for me and Lewis to have to leave our family home at such a traumatic time. I somehow got Lewis through his GCSEs and then it hit me like a brick wall. One night as I sat down to dinner and lifted my fork of spaghetti Bolognese to my mouth, the force hit me though someone had punched me in the stomach. I just went to pieces. I cried and cried and I couldn't talk.
42. The grief I felt was like nothing I could ever imagine experiencing. I had a total and utter and catastrophic breakdown. I couldn't speak to anybody; I didn't want people to talk to me. I just wanted to sit in a corner with a duvet over my head. That was a very, very dark time for me. It hurt even to make decisions, even whether or not I wanted Marmite on my toast. He'd been my life. He was my everything.

Paul

43. In 2009 Lewis set me up a Facebook profile. One day I left a comment below a friend's post, I can't remember what, something throwaway and Paul (a friend of a friend) responded to my comment. I responded to Paul's response, and he responded again. Then he sent me a friend request.
44. We exchanged private messages like 'How old are you?', 'I keep dogs', 'I love dogs too'. Private messaging turned into texting and texting turned into phone calls, two or three times a day. We spoke about our childhoods and I mentioned that I was a widow. Then Paul happened to mention, in passing, that he was 'poorly'. "You can't just say something like that and leave it hanging there" I told him. Paul then told me he was a haemophiliac.
45. I explained that I knew all about the condition and told him about Jeremy. I'd lived with haemophilia so there was nothing he could tell me that would shock me. The coincidence was striking. I wasn't looking for another husband, let alone a husband that had haemophilia but that was how things turned out. We met up in person and hit it off immediately. It was like we had known each other for years.
46. Paul was a gentle man as well as a gentleman. He was gently spoken with a quick, dry wit. He called me his 'posh bird'. To me, he was "Hoops". He'd stand up when ladies entered the room. He was quite unlike anyone I had met before.
47. Both Paul and I were emerging from dark periods of isolation when we met each other. Paul had been the victim of a nasty and unprovoked attack in the street. He'd stopped taking combination-therapy drugs for his HIV until I told him he was being selfish and ordered him to go back on them. We saved one another. We came together at a time when we both needed one another. He helped me crawl out of that horrible place I was in.
48. By the time we moved in together in Kineton, Paul and I had settled into the routine of a happy middle-aged couple. Paul's mobility was reasonably good

in comparison to Jeremy's. We would wander semi-aimlessly around the shops in Stratford-upon-Avon, and take trips to Bath and Paris. There was a village near our home called Wellesbourne that had a small airfield, and we would go to watch the planes take off and land.

49. Overall Paul's illness had a much greater impact on his life than Jeremy's. There were endless hospital visits and check-ups for the HIV, the HCV and the Haemophilia. Paul couldn't drive so I would have to accompany him to the clinics. I was learning for the first time the scale of the Contaminated Blood Scandal. Paul really opened my eyes to it.
50. Paul had an attempt at HCV clearing treatment. He was on it for about a week but he reacted violently to it. It made him very sick and have bad diarrhoea. They then said he could try again once his system had cleared it. His health deteriorated and he could not try again.
51. Paul had liver cirrhosis, high blood pressure, kidney disease, arthritis and ongoing immune issues. One morning in November 2015, Paul woke up with a headache that wouldn't go away. When it finally cleared up, he told me he had a 'wiggle' in his line of sight. Eventually, it turned into a blind spot. When he went to the hospital to get it checked out, the doctors found his blood pressure had sky-rocketed. He'd had a stroke, and his eyesight deteriorated over the next few months to the point where he was registered blind.
52. Paul's loss of sight was extremely distressing for him and it transformed our relationship. Paul was terrified of making a fool of himself and didn't like to leave the house much. We were trapped indoors but the experience brought us closer. Paul's health became precarious. He'd have seizures and, one day when he had been hospitalised for sepsis, a doctor warned me that he could die at five minutes' notice. Somehow, he kept bouncing back. His sight was gone for good, but his sense of humour was intact.
53. One morning Paul woke up and told me he didn't want breakfast as he was feeling bloated. Half an hour later he vomited on the bed and lost control of

his bowels. I helped him up on to a commode we kept in the room, stripped him off and began cleaning him up. I then called 999.

54. Whilst waiting to be airlifted to hospital all hell broke loose. Paul went into cardiac arrest and had to be resuscitated with a defibrillator. The doctor told me to prepare for the worse. He had two more cardiac arrests on the way to hospital. There wasn't much more they could do for him. Paul was unconscious but I went into intensive care to say my goodbyes and tell him that I loved him. For the second time in less than a decade, the Contaminated Blood Scandal had left me bereaved.
55. Paul worked as a civil servant working for the Armed Forces Pension Service and was made redundant after his employers found out he was HIV positive. Paul referred to himself as 'medically retired'. He was unable to get a job from that point onwards because no one wanted to employ someone with HIV. He was supported by the MacFarlane trust, Skipton and DLA. All of his income was benefits and trust money.
56. He kept himself busy with activism. He was part of the campaign to get to the bottom of why the Contaminated Blood Scandal had happened in the first place. He'd go on demonstrations and visit Downing Street bearing petitions and demanding answers. Paul was a member of Tainted Blood. He was known in the Tainted Blood community. He referred to them as the 'lads'.
57. As I was Paul's full-time carer, most of my income died with him. I was on the wrong side of 50 and had not worked for 6 years.

Section 6. Treatment/care/support

58. Neither Paul nor Jeremy were offered any counselling or psychological support.
59. Paul was never lucky enough to become a parent. He told me that he was approached by the Italian doctor and he did something on 'Tomorrow's World'

about sperm washing. He was a guinea pig for pioneering IUI sperm washing treatment that led to many haemophiliacs with HIV to be able to have children. Paul and his then partner were not successful.

Section 7. Financial Assistance

Jeremy

60. Jeremy and I had no financial support except for Jeremy's Disability Living Allowance.
61. The Consultant from Warwick Hospital that signed Jeremy's Death Certificate informed me that I was eligible for a payment from the Skipton Fund after Jeremy died. He said as Jeremy died as a direct result of HCV I could apply. Jeremy's sister Julia was with me. I received £25,000 by way of what I believed to be a stage 2 Skipton Fund payment. I used it to buy a car and I took Lewis away on holiday. I gave some money to Jeremy's family as my loss was their loss too. I have very recently found it through EIBSS that I never received the Skipton Fund Bereavement payment of £10,000. I would not have known had Tainted Blood Widows not advised me to ask them to check that I had had everything I was entitled to. It is only 11 years late in coming to me.

PAUL

62. EIBISS have been nothing short of rubbish. They are unhelpful and totally inept. When I informed them that Paul was dead they literally pulled the rug of support from under my feet. They stopped his payments as soon as I sent them the Death Certificate. They did not tell me about top up payments, a friend later did. After sending them a ludicrous amount of information and evidence in relation to my own financial circumstances, I was then told that the top up payments could not be my main wage and that I need to get a job.

I was in a terrible state worrying how I was going to find a job at my age without a recent work history. Another friend took pity on me and offered to pay me a wage in return for cleaning out the stables at her yard. I was then told by EIBISS that I needed to apply for Universal Credit so I went through the horrendous ordeal of applying and waiting for that.

63. Whilst all this was going on, all I had was my £179 monthly widow's payment from Jeremy. My son and my 87 year old mother were keeping me from the December through to the April and I could not pay my mortgage.
64. When the top up came through I still couldn't afford to pay the mortgage and I could barely afford to eat. I think I received approximately £1,000. My mortgage repayments were approximately £700. I lost my home again after a second bereavement. The building society were patient but it took me a year to sell and I had to drop the price of my home due to the risk of repossession. In fact, I received the letter threatening repossession proceedings as soon as I accepted the offer. Last year was the worst year of my life. I have downsized again to a leasehold maisonette. I am at last mortgage free but I do have to pay service charge and the ground rent.

Section 8. Other Issues

65. I do not have Jeremy's medical notes and records. Paul tried to get his medical records without success. He was in hospital one day and 'nicked' them (as he put it). He returned the documents after reading them and was reprimanded by the hospital for taking them. He told me that there were glaring omissions in what he saw.
66. I have known and lost two of the best human beings ever to have walked this earth. For me it is about answers. I want to know 'why?'. I am honoured to have known both of them, I really am. I've been a privileged, privileged woman. I had my first love and I had my soulmate. They'll always be with me and I will love both of them equally. My heart overflows with love for the pair of them. They're amazing men, and they need their stories told, both of them.

Anonymity, disclosure and redaction

67. I am not seeking anonymity and I understand that this statement will be published and disclosed as part of the Inquiry. I wish to give oral evidence to the Inquiry. The only thing I can do to help Jeremy and Paul is to tell their story.

Statement of Truth

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

Signed.....

GRO-C

Dated.....

30-7-19