

Witness Name: A Beesley
Statement No: WITN1090001
Exhibits: WITN1090002-20
Dated: March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF AMANDA BEESLEY

I, Amanda Beesley, will say as follows:-

Section 1. Introduction

1. My name is Amanda Beesley, I was born on GRO-C 1961 and I live at GRO-C
GRO-C
2. I make this statement as an affected person in relation to my late husband, Andrew Michael Beesley, who died as a result of receiving contaminated blood products. Andrew was born on GRO-C 1966 and he died on 15th March 1999.
3. **This statement has been prepared without the benefit of access to Andrew's full medical records, but some records are available and where appropriate I refer to them.**

4. I am prepared to give a separate statement in relation to my employment with and time spent at Lord Mayor Treloar's College in Alton, Hampshire (LMTC) which, I am told would require a separate Rule 9 request for evidence from the Inquiry.

Section 2. How Infected

5. Andrew suffered with severe Haemophilia A and was diagnosed in or about February 1969 following a referral by his GP to Great Ormond Street Hospital (GOSH) to which exhibit **WITN10900002** refers. It appears from his notes that there was a family history but this was unknown to his parents. GRO-C

GRO-C

6. Andrew told me that he was given both Cryoprecipitate and Factor VIII blood products which is recorded in his NHD notes and I refer to exhibit **WITN1090003**.
7. As a result of receiving contaminated blood products, he was infected with HIV and Hepatitis C.
8. Andrew's Haemophilia put his family life under a lot of strain when he was a young boy. He had to travel from his home in Crawley in Sussex to GOSH for treatment. He would be admitted to the hospital then back at home only for a couple of days before the routine was repeated again.
9. Andrew's notes record that in August 1972 his treating physicians at GOSH suggested that he be temporarily treated prophylactically with Cryoprecipitate two or three times per week by his GP or at Andrew's local hospital in Crawley. This proposed course of action was discussed with Andrew's mother and she agreed that it was worth trying in order to reduce his incidence of symptoms and the consequent strain on him and his family. I refer to exhibit **WITN1090004** in this regard.

10. GOSH's notes record that Andrew's GP was willing to try giving him the prophylactic treatment and that his mother was also learning how to give injections with home treatment to start in September; exhibit **WITN1090005** refers.
- 11.
12. This meant that Andrew could be treated at home and, from his notes, appears to have led to an instant (and ongoing) improvement and he did not miss so much school; exhibit **WITN1090006** refers.
13. In September 1977, aged 11, Andrew joined LMTC in Alton, Hampshire which had a Haemophilia Centre on site, easing the pressure on his parents. A letter (February 1997) from C A Sieff (lecturer in haematology) notes that *".... It would be a very good idea for him to go to Alton, as they have facilities for prophylactic treatment as well as considerable expertise in the management of severe haemophilia. This would result in him losing far less time from school than if he went to a normal school and I am sure this would be best for him in the long term"*. I refer to exhibit **WITN1090007** in this regard.
14. The school Medical Officer, Dr Painter, wrote to the consultant paediatrician at Andrew's local hospital (Horsham Hospital) regarding Andrew's treatment. Interestingly, he notes that *"... as the Hepatitis Survey, about which Dr Kirk wrote to you in the past, is now finished it would seem likely that there would be no restriction on material and that he could be treated with a concentrate or Cryoprecipitate as available"*. This is evidenced in exhibit **WITN1090008**. It is notable that Andrew's medical records do not contain any letters from Dr Kirk. Furthermore, there is another letter of 26th July 1977 which is not contained in Andrew's medical records.
15. There is an undated form which records that Andrew's mother, Mrs Gillian Barbara Beesley, agreed to Andrew taking part *"in a trial of a new Factor VIII product as explained by Dr Aronstam"*. A manuscript note in the corner of the

page on the form refers to Armour but there is no further information. There is no written record of the explanation given by Dr Aronstam. Andrew's detailed treatment records whilst at LMTC, together with available bleeding and treatment records from this time are exhibited at **WITN1090009**.

16. It may be that the consent above is in connection with the "*study of the half-life of a new preparation of factor VIII*" referred to in what appears to be a generic letter dated 02 June 1980 (sent to Dr Peard (Horsham) and Dr Hann (GOSH) as evidenced by exhibit **WITN109010** in which he also refers to a previous letter in which he says he "*... erroneously stated that this project was on behalf of the Haemophilia Centre Directors of Great Britain. In fact, it is a project merely at the discussion stage in the Working Party on home therapy and prophylaxis...*". I can confirm that the letter, to which the above was replying to, is not contained in Andrew's medical records.
17. On 5th September 1980 Dr Aronstam again wrote to Dr Peard and Dr Hann stating that it was felt "*he is now ready for training in self therapy and if you agree, could you let me know what material you would like us to train him*". Exhibit **WITN1090011** refers.
18. On the same date, there is a copy of a generic letter sent to unidentified parents, in which Dr Aronstam states that he had written to them the previous year and that they had "*kindly agreed to the trial of a new product*" on their son. He goes on to say that "*The manufacturers were not able to produce stocks of the material in time for us to do the trial last term, but there is a possibility that we may undertake the trial over the next two terms...*" and that he hoped that they would still agree to their son taking part in the study. I refer to exhibit **WITN1090012** in this regard.
19. This letter has been annotated with manuscript question marks and with the word "*what*" by person(s) as yet not identified.

20. On 17th September 1980, Dr Peard thanked Dr Aronstam for his letter and noted that *".... it is important that research should continue into the best treatment of Haemophilia, and I would support your request to the parents that Andrew be included in the anticipated double-blind uncontrolled trial of the new preparation of factor VIII"*. Exhibit **WITN1090013** refers.
21. Save for the undated form there is no record in Andrew's medical notes of correspondence and/or meetings and/or discussions with Andrew's parents regarding this specific trial or the risks involved.
22. On 22nd September 1980 Dr Peard wrote to Dr Aronstam suggesting that Andrew *"be trained in the use of Factor VIII"*. She said that they only had access to Cryoprecipitate which had to be kept deep frozen and that *"there would be no question of him having Cryoprecipitate stored at home"*. She referred Dr Aronstam to Professor Flute at St Georges where there was a Home Training Scheme and noted that she had tried to obtain Factor VIII for home use outside that scheme but without success, which she attributes to the *"present climate of financial stringency"* to which exhibit **WITN1090014** refers.
23. On 26th September 1980 Dr Aronstam replied noting similar problems with financial stringency and that they could not supply Factor VIII outside of term time. He also noted that Andrew's parents were *"contemplating transferring him to a physically handicapped class in Crawley in the New Year – in which case, you would need to find the factor VIII necessary for his treatment all year round"*. This is attached at exhibit WITN1090015.
24. On 25th September 1980 Dr Gorman at GOSH confirmed that he *"has been using dried Factor VIII concentrate rather than Cryoprecipitate and we should be happy if he is trained in one of these concentrates"* to which exhibit **WITN1090016** refers.

25. On 1st October 1980, Dr Peard confirmed that Dr Aronstam should teach Andrew how to inject himself, using Cryoprecipitate, and I refer to exhibit **WITN109017** in this regard.

26. Once Andrew's parents realised that Factor VIII could be a well-managed home treatment, he returned home at the age of 15 and attended a mainstream school, with a unit for pupils with disabilities, in Crawley.

Communication regarding HIV status

27. Andrew's mother told me that she called St Thomas' hospital the day after they saw Andrew's haematologist, Dr. Savage on television, talking about HIV infection in haemophiliac patients. She asked if Andrew had been infected and was told he was HIV positive. They were given this news over the phone with no lead up to it and no support to deal with it. Andrew's parents could not face telling him but instead, encouraged him to go to the hospital himself to be tested.

28. It is stated in Andrew's medical records (in correspondence in later years) that Andrew was tested for HIV on 13 December 1984 and that that test was positive but there is no reference to that test or any communication with his parents at that time. Andrew would have been aged 18 at this time.

29. There is further reference to testing in or about June 1985 to but again this was definitely not communicated to Andrew.

30. I know this because in February 1987, Andrew and I went to St Thomas' Hospital together in order for him to be tested for HIV. I remember that after the blood was taken to be tested, the nurse said "*don't forget to come back for the results this time*" which seemed a bizarre comment at the time. Now, I know that it was because he had been tested before.

Section 3. Other Infections

31. I am aware from Andrew's medical records that Dr Wasseff, of LMTC Haemophilia Centre, was sent a letter by BPL at Elstree informing him that "*a batch of Factor VIII could potentially be infected*" and confirming that the Centre had "*received 150 vials of Factor VIII batch number FHC 0204 on October 1989 (sic)*" to which exhibit **WITN109018** refers.

32. It then appears that Joan M Trowell, Hon. Consultant Physician decided that "*it would be interesting to follow the titres of his anti hepatitis B antibodies*". Exhibit **WITN109019** refers.

33. We did not know about the risk of vCJD while Andrew was still alive. I heard on the radio one night that all haemophiliacs were at risk of vCJD and I remember thinking that I was glad Andrew was not alive to hear that.

Section 4. Consent

34. I refer back to my statement above in terms of consent given (or not) by Andrew's parents but I do believe that Andrew was tested for both HIV and Hepatitis C without his knowledge and therefore without his consent.

35. I can see from Andrew's medical records that he was tested for Hepatitis C in June 1990 with a first-generation test which was confirmed with a second-generation test on 27th November 1995 as confirmed in exhibit **WITN109020** and I am sure that he was not told that he was being tested.

36. I do not recall any unexplained tests in relation to myself. I had a number of HIV tests as the "*wife of a HIV positive haemophiliac*", the results were all negative.

37. I strongly believe that Andrew's parents would not have consented to Andrew being used for testing new drugs if they had known of the risk of infection.

38. I recall that boys with haemophilia were used for "*research*" at LMTC. To my understanding, LMTC looked after the largest group of haemophiliacs in the world. They would have been an attractive group for researchers to target, being such a large group, living in a relatively controlled environment, with medics in a position to monitor them closely because they were seeing them regularly. I think I knew they were trying new treatments, but I would never have thought they would come at such a risk. I do not remember thinking that Factor VIII was experimental.

Section 5. Impact

My life with Andrew

39. I first met Andrew at LMTC when I was aged 18. I went to work there as a member of the care staff with the intention of going to university to study English or Fashion Journalism a year later. In the event I stayed for 2 years and changed my career choice to Occupational Therapy (OT).

40. Andrew was a student in the boarding house that I was employed in as a house parent. He was one of many haemophiliac boys at the school. I loved my time at LMTC and enjoyed spending time with the students. Andrew was intelligent, lively, good humoured and mischievous. He did not need personal care like the other children with spina bifida, muscular dystrophy or cerebral palsy so I had limited contact with him. However, I enjoyed talking to him at meal times and when I was tasked with going "*on the van*" with the boys who were travelling up to the Haemophilia Centre at the Holybourne site. I also remember scribing for him when he was in the school "*sick bay*" with bleeds in both elbows, and once,

having to cut the seam of his pyjamas open because the Haemophilia staff had plastered his arm with his pyjama top on and so he couldn't take it off.

41. The atmosphere at Treloar's was always upbeat and the school was always full of life. All the children were valued for who they were, and the haemophiliac boys were no exception. They brought a lot of fun into school life. They were generally bright and able boys. However, from what I have seen and heard in more recent times, it appears that there were people in government and NHS departments who thought that haemophiliacs were just a burden on resources. That they could be experimented on and their lives put in jeopardy. At Treloar's we believed the boys had something to offer and a lot of them were capable of achieving good careers.

42. Andrew left LMTC around Christmas 1980 and I left in 1981. I kept in touch with him with sporadic letters for a while but did not see him for several years. I wondered how he was when we heard about the boys being infected with HIV, but I didn't contact him. One of his old dorm mates (who was still at LMTC) visited the Lower School after the exams at the end of the summer term and we speculated as to how Andrew was. I decided to write to him. He didn't write back but turned up at LMTC one day soon after this. He was 19 at the time.

43. Andrew did not know if he was infected or not. He was not attending the hospital as his parents were collecting his Factor VIII for him. I know his parents had regularly told him that he needed to go to the hospital as the hospital staff wanted to talk to him, but they did not say why.

44. After the summer holidays, Andrew came to see me again. We talked for hours and I loved being with him. We started going out soon after, in about November 1986. We talked about getting married and having children. We also talked about the need for Andrew to be tested for HIV. In February 1987, we travelled to St Thomas' together for him to have the test. As I said above, I thought that it was

odd that as we were leaving, one of the nurses said, "*don't forget to come back for the results this time*". Andrew did not know about any previous testing. We had to wait two weeks for the result. We travelled to London with heavy hearts, but we had some hope because, at the time, we had no idea how high a percentage of haemophiliacs had been infected.

45. Two weeks later we returned to St Thomas' together find out about Andrew's HIV diagnosis. I remember the nurse walking us all the way across the hospital from the Haemophilia Unit into the old part of St Thomas'. We walked up the big wooden staircase and into a horrible dark room, where inches away from the window to the outside of the building was a brick wall. I remember this day very clearly and I remember that there had been no attempt to make the room look cheery; there were no pictures on the wall, and we sat in low chairs opposite each other next to an old gas fire. Apart from the nurse telling us that Andrew was HIV positive, I do not remember much else. She spoke a lot, but I do not remember any specific information being given to us because all I wanted to do was to get out the room and be with Andrew. We received such awful news in such an awful room. I remember thinking; "*please just let us go*". I also remember staring at a Monet print when we were kept waiting in the haemophilia unit afterwards for treatment supplies thinking "*there goes our family*".

46. I don't remember when we were given Andrew's prognosis, but I know that we were told at some point that Andrew would probably only live for about another two years. We were devastated and fearful of what was going to happen to him. It was a time of immense sadness.

47. Andrew had been working in IT at Duracell in Crawley. We started looking for jobs so that we could be together. I would have moved to Crawley, if necessary, but Andrew applied for and was appointed to an IT position at LMTC. We were so excited. I remember the day of his interview and appointment clearly because

Style Council had come to play for the students, and it was such a happy day all round.

48. Andrew lived at my parent's house and I lived at LMTC accommodation with two flatmates, one of whom was Jane Kershaw, the haemophilia nurse at the time.

49. We became engaged in May 1987 and married on 15 August 1987. We initially lived in a rented flat in Alton but were able to move into a flat at LMTC, which was tied accommodation, early the following year.

50. I found it very difficult to cope with Andrew's diagnosis and prognosis. We knew that there was a risk of me becoming infected with HIV from sexual intercourse and I was very fearful of this; not so much for me but for any baby that we may have produced and also for Andrew himself and my parents who would have been devastated if I had been infected.

51. I wish we had received advice beyond how careful we had to be (at one time I was told I needed to use a cap as well as condoms). We were made to feel that any sexual contact carried a very high risk.

52. I suffered from a low mood, and when we had happy times, my happiness was punctuated by knowing that Andrew was likely to die in the near future and that I would lose him. We were very close, not particularly in the way of sharing interests, but in terms of a shared sense of humour, values and attitudes. We felt a deep connection and felt we belonged together. We both found it very difficult that we could not have children. I had always wanted a family and had never really been interested in a career. I wanted to have children and devote myself to caring for them and for my husband. It seems an old-fashioned view now, but it wasn't so odd then.

53. In an attempt to realise our dream of starting a family, we were referred by our GP, Dr Andrew Sword, to James Pringle House in London to discuss the

possibility of having Andrew's sperm frozen until such a time that we could find a way for me to become pregnant safely. However, it turned out that this was not a viable option because the hospital would not take/store sperm from someone who was HIV positive. They explained this was because of the risk that it could be mistakenly given to someone else.

54. I then read about a sperm-washing treatment programme which was available in Italy. Andrew and I were referred, again by our GP, to a hospital in Basingstoke where a consultant shared his thoughts on sperm washing with us. He carefully explained what the procedure would be but ended up saying politely, what amounted to, in other words, "*I wouldn't touch it with a barge pole*". However, the consultant was happy to conduct a number of tests for us in order that we could commence the treatment in Italy which was very helpful.

55. The treatment in Italy turned out to be a truly awful experience. When we arrived at the Italian hospital, in Milan, I was instructed to wait outside a room with no explanation given. When I was called into the room, I underwent an internal examination and because I had not expected this, I was naturally very tense throughout the procedure. At this point the doctor said "*why are you like this? This does not hurt*". I was extremely upset by the lack of empathy and the brusque approach.

56. The actual insemination appointment was a heart-breaking experience. Whilst the doctors carried out the procedure on me, Andrew was stood in the corner of the room holding our coats. It was all so clinical, and I started crying. The doctors asked me why I was crying, they had never known anyone cry during the procedure before. I told them it was because it seemed such a horrible way to have a baby. Following this I bled on the aeroplane, on the way home, and the procedure was ultimately unsuccessful. Finding out I was not pregnant was devastating for us both.

57. Soon after our return from Italy, we were told that sperm washing was to become available in the UK in about 3 months' time. We therefore did not return to Milan for another attempt, thinking it would be easier and better to be seen in London. However, there were some issues with an Ethics Committee and as a result of this the start date kept being delayed. I was approached to be interviewed for an article which was to be published in the Sunday Times. I was told that the story was to highlight our plight and support the proposal to have sperm washing made available to us in the UK. However, the article described us as "*irresponsible people*" and basically criticised our desire to have children. I was later told that the article further delayed the approval of the Ethics Committee.

58. I received a letter inviting Andrew and me to the clinic for sperm washing at CWH only two days after Andrew had died. I telephoned them to inform them of his death and was later reassured by Andrew's consultant, Dr Asboe, that he had tried to stop the letter coming out to me but had been too late. However, six months later, I received a further letter questioning why we had not proceeded with the treatment. I couldn't believe that a department dealing with HIV positive people would not be aware that there was a possibility that a patient had died and check before sending out a letter chasing them. It felt like having salt rubbed into the wound of my childlessness.

59. I was, and still remain, deeply saddened that I was never able to have a baby with Andrew. Indeed, in Andrew's generosity of spirit, he even suggested I have an affair so that I could have a baby. However, the only baby I wanted was Andrew's.

60. The inability to have children resulted in a degree of social isolation for us as a couple. Our friends all went on to have children and social occasions became centred around children which excluded us. We ended up not wanting to meet new people because we did not want to explain our life story nor disclose the fact of Andrew's infections because of the stigma attached to HIV.

61. After a couple of years of marriage, I changed jobs from being a unit leader on the care staff at LMTC to working as an OT at Social Services. I changed jobs so that I would not be working shifts and we could see each other more. Then an OT job came up at the school site of LMTC which I successfully applied for. Andrew was still working at LMTC but mainly on the college site. I remember one day unexpectedly seeing him at the school site and literally feeling weak at the knees as though I had just fallen in love at first sight.
62. Andrew wanted to develop his career, so he applied for an IT job at a local sixth form college in Alton. He was getting on really well in his first week but then, when he was going to attend to a problem on someone's computer, he saw a memorandum to alert everyone that a new member of staff had HIV. This memorandum also advised that the staff should take precautions regarding blood spillage etc. Andrew said that he wasn't named but it wouldn't take a rocket scientist for people to put two and two together. He was devastated. He then went on sick leave with a cold or flu and he never went back as he couldn't face people knowing about his infected status. We were then down to managing on my income alone.
63. We had always been told that we should not apply for a mortgage because it would be impossible for us to obtain one. At one point Andrew started a business with his friend Tim. They obtained contracts with local businesses in relation to managing their IT issues and I do think that they would have been very successful because both Tim and Andrew were hardworking and talented at IT. However, ultimately Andrew's health difficulties meant that this joint venture was short lived.
64. Unfortunately, the same was true in relation to Andrew following a degree course with the Open University. He followed the course for a year but then wasn't well enough to continue. He was very intelligent. For example, he wanted to learn to write computer programmes in the language "C". So, he bought a textbook on it, read it and could then do it. I believe that Andrew would have been extremely

successful if it was not for his infections. He had the intelligence and talent to do well in IT at a time when IT was really taking off. He could have had a great career. The sky was the limit but for his infection-related health issues.

65. One day, I don't recall when, but I believe that it was in the early to mid-1990s, we were given the bad news that Andrew's CD4 count had fallen to dangerously low levels. Andrew was therefore put onto AZT but it made him feel unwell and he told me wasn't prepared to live like that, so he stopped taking it.

66. The first time Andrew was really poorly was when he was started on prophylactic treatment to reduce the risk of pneumonia. Without any prior warning that it might happen, Andrew had a severe reaction to the Septrin. I was so frightened by his symptoms that I called the Haemophilia Unit expecting them to send a nurse out to see him but instead they just told me to give him some Piriton expecting me to have some at home, or I suppose, to leave him on his own to drive to town to buy him some.

67. That was the start of about 5 years of illnesses which were always related to reactions to the drugs that he had been prescribed. Every HIV treatment he was prescribed caused serious side-effects. Some of these were life-threatening.

68. When his CD4 count plummeted further, I was concerned that the doctors at the LMTC Haemophilia Unit did not know enough about HIV as they were always referring to talking to colleagues in London for advice. I wanted to "*cut out the middle man*" and spoke to our GP about it. He referred us to the Chelsea and Westminster Hospital (CWH). This angered the doctors at the Haemophilia Unit who never forgave me for this.

69. In retrospect, I do not know if we did the right thing. The HIV care at CWH was comprehensive with many more checks and the consultant, Dr Asboe, was easy

to talk to and knowledgeable about the most up to date HIV treatments. However, he was not very knowledgeable about haemophilia and how the HIV drugs might affect Andrew in respect of bleeds. This led to Andrew being given medication which caused him to bleed into his muscles which was very painful for him.

70. At least one of the treatments also gave him nightmares which frightened me. He used to talk a lot in his sleep when on this drug and experienced all sorts of muddled, nightmarish visions.

71. The treatment also gave him peripheral neuropathy which he described as *"having red hot poker forced up through his feet into his legs"*.

72. He also suffered with pancreatitis and kidney stones, both caused by the HIV drugs. When he suddenly became acutely ill with kidney stones, I was 15 miles away in the hairdressers. He called the Haemophilia Unit at LMTC but instead of calling him an ambulance, they told him to get himself to hospital. He called my mother who drove him as fast as she could to Basingstoke. When she dropped him off to go in whilst she parked, he vomited at the hospital door because of the pain. My mother called the hairdressers to get a message to me and I rushed to the hospital as quickly as I could. I didn't know what was wrong and feared Andrew might die before I got there.

73. At some time, Andrew was hospitalised for a month after developing pancreatitis which had almost killed him. His mental health deteriorated, and, in a confused state, he attempted to swallow a knife in order to take his own life. I was told he needed 24/7 care, but they could not provide that from hospital resources, so I slept on the floor beside his hospital bed and it was incredibly grim. There was nowhere to get any food and I had to rely on Andrew's mother visiting the hospital to allow me to go home to have a shower and get a change of clothes.

74. I had my suspicions that Andrew's Hepatitis C had taken its hold on him when he became extremely fatigued and lethargic and spent a considerable amount of time asleep on the sofa. I recall coming home from work at lunchtimes to check on him and, once I had ascertained that he was still breathing, I returned to work. I know this sounds like bizarre behaviour. It was a very odd surreal time and I questioned whether I was actually exaggerating these circumstances and experiences in my head.

75. Andrew's parents really struggled with his infection as naturally, they were devastated that this should have happened to their son.

76. I had really hoped that Andrew would have been able to die peacefully at home but unfortunately this was not the case. After exhausting the HIV treatments on offer at the time, he became poorly with a chest infection and was hospitalised with pneumonia for the last two weeks of his life. I kept hoping that he would improve and could then be discharged home. I didn't think Andrew would die of his first HIV-related/AIDS illness and thought pneumonia was treatable. However, they failed to get a sputum sample and so were not sure what infection they were treating. The doctors told me they didn't believe Andrew had pneumocystis because he had been having Pentamidine prophylaxis. (I later learned from Dr Asboe at the CWH that this assumption was incorrect because the inhaled Pentamidine did not always reach the bottom of the lungs.) I realised how ill Andrew was, and that he might not survive the pneumonia when Dr Roy, one of the haematology doctors, asked me on the Friday afternoon for permission to invoke a Do Not Resuscitate (DNR) Order. He advised me to give permission, partly because of the risk that resuscitation could cause internal bleeding and partly because of the severity of Andrew's symptoms. Immediately after I had given permission I had to walk back to Andrew's room knowing that there was a likelihood he could die in the next few days. I made the decision not to tell him about this, unless he specifically asked me. Despite me being unable to hold

back my tears, upon my return from seeing Dr Roy, Andrew never asked me what Dr Roy had said, so I never told him.

77. Andrew passed away early on the Monday morning. At one point during the night before, he lost consciousness and then suddenly sat up in his bed and said to his mother and me *"I've died, haven't I?"* I think he may have seen a vision of a garden because later on he said he wished he could open the door and go out into the cool garden. He held onto life, gasping for breath with his oxygen levels going down lower and lower. I had heard that sometimes people held on to life, waiting for permission from their loved ones to go. I didn't want Andrew to suffer any more so, having told him how much I loved him and how precious he was to me, I suggested he open the door and go into the cool garden. He died minutes later. Andrew was finally at peace and I feel so truly privileged that he was a part of my life. I have held onto a hope that one day we can somehow be reunited and I long for that day.

78. I have such precious memories of Andrew. He was a beautiful man, both inside and out. I look back through photographs and sadly, some show how incredibly poorly he looked, particularly towards the latter stages of his life.

79. Andrew's funeral was a difficult but beautiful event in the church next to Treloar's School. I didn't want it to be a "celebration" of his life, given what he had been given to deal with, but I wanted it to be a thanksgiving for him having been part of our lives. One of his close friends played two pieces of classical guitar music that Andrew had once mentioned he would like played at his funeral and another read a poem. His interment was a private affair with just family present at the graveside. Andrew had not wanted his friends to see him in the latter stages of his illness and so I did not think he would want them to see him being lowered into his grave. Also, I could not face seeing and talking to anyone.

80. Andrew's friends and colleagues tried to provide me with support in the early months following his passing. They had lost a valuable friend and colleague and I

think that it helped them to talk about him with me. In an effort to support me, they invited me to their social events, which was lovely, but I never went as it was too early to cope with being with other people.

81. I have never stopped grieving for Andrew, and it is not an easy thing to live with. The ongoing disclosures of information relating to the infected blood products means that emotions are constantly being stirred. I miss Andrew more than can be put into words. He was my best friend and loved me unconditionally. My grief persists and I cannot see it disappearing.

Section 6. Treatment/Care/Support

82. After Andrew's attempt to take his life, he was offered psychological support in the form of sessions with an Art Therapist, but he felt that it was nonsense and did not feel that it was of any help to him.

83. Andrew's medical records stated that I would need psychological support following his death, but this never materialised.

84. I felt a huge hostility and sense of competition from the Haemophilia Unit towards the CWH. I felt that the doctors at the Haemophilia Unit were extremely angry with me for taking Andrew to CWH for treatment and this influenced some of their clinical decisions.

85. We found the treatment we received at St Michael's Hospice in Basingstoke appalling. I think Andrew was admitted there after his pancreatitis as a half-way to returning home. The staff displayed little empathy towards us and no understanding of Andrew's health status at that time. Within an hour or so of being admitted, he started to pass blood in his urine, which was most likely a haemophilia related problem. He had not had this happen before, so we were

worried about it. I asked the hospice staff to contact the haemophilia doctor, but they would not. They treated me as though I was exaggerating the urgency of the situation and were trying to talk to me about accepting that Andrew was terminally ill instead of getting him the medical attention he required. At this stage, he was not dying but I was frightened that he could die of a bleed if not treated. I cannot describe the anguish I felt trying to convince them to get appropriate help.

86. On one particular occasion, Andrew was admitted to Basingstoke District General Hospital in the night with what turned out to be septic arthritis. There was no haematologist available, so he was seen by a doctor who did not know him and appeared not to know about haemophilia. They were not able to do anything for him but wanted to admit him all the same. He was placed on a general ward next to somebody who had a horrendous cough which the nurses told me was because of a chest infection. I had to tell the medical staff that this was not acceptable. I told them Andrew's CD4 count was extremely low and his viral load was high but they looked at me blankly. They had no understanding that Andrew had an almost non-existent immune system and therefore needed to be protected from infections. I checked what Andrew wanted to do and then told the doctors I was taking Andrew home and would take him back in the morning when we could see a haematologist and receive appropriate treatment. I had to be Andrew's full-time guardian and a gate keeper in order to protect him. I had to bolster myself in order to be assertive when interacting with the medical practitioners. I knew they considered me over-involved, but experience was teaching us to be increasingly distrustful of medical staff and putting us on guard against them making mistakes.

87. When I was about to marry Andrew, our GP, Dr Andrew Sword, told me that he would not necessarily know what we would need in future, but we should feel free to ask him for anything and he would always do his best to help. He was

true to his word and I remain thankful to him to this day for his kindness and support.

88. The whole GP practice was wonderfully supportive, but they were not familiar with HIV and the side-effects of the medication. On one occasion Andrew saw a GP who told us that his reported symptoms were due to indigestion, when he actually had pancreatitis. I do not blame them for this reasoning as the symptoms on most patients they saw would have been due to indigestion. However, it was difficult having no-one who appeared to be knowledgeable in relation to HIV combined with haemophilia, so we ended up having to take on the role of our own experts in order to manage Andrew's symptoms and health issues.

89. I wished that there was a helpline to call which offered a single point of medical advice. Nobody was proactive regarding our needs or with regard to how those needs could be met. When I sought support from a local HIV service and spoke to their nurse, I ended up being chastised by the haemophilia doctor because the haemophilia nurse was apparently upset by my seeking advice from another nurse.

Section 7. Financial Assistance

90. When we moved into our tied accommodation in the first year of our marriage, we received a grant from the Macfarlane Trust for new carpets. There was rarely a social worker in post working with the patients at the Treloar Haemophilia Unit so we were not supported to apply for assistance that we may have been entitled to.

91. We applied for financial help towards going to Italy for the sperm washing programme. However, this was refused due to the perceived risks associated with the programme. The Macfarlane Trust demonstrated a very paternalistic view and did not allow us to make a decision about the risks.

92. I applied for a grant to assist with Andrew's funeral expenses. I naively thought that The Macfarlane Trust would cover the costs of the funeral, but I was told the standard grant was only £1000. This figure was eventually doubled after an emotive telephone call with them. Andrew did not have a lavish funeral, because that would not have been what he would have wanted, but his funeral was beautiful.
93. I applied for some Macfarlane Trust grants following Andrew's death when I was made aware by other haemophiliacs that I could do this. The trust helped to fund roof repairs when I purchased my first property and could only afford somewhere in need of restoration. They also helped me to pay for a course to learn how to overcome chronic fatigue (brought about by long-term stress), and later to pay a deposit for a car.
94. I received the widow's payment from The Skipton Fund many years after Andrew's death. I had to provide them with the evidence that Andrew was infected with Hepatitis C.
95. Recently, I received a letter stating that I was entitled to a winter fuel payment from the EIBSS. There was no explanation as to why, 20 years after Andrew's death, I was suddenly entitled to this.
96. I also approached EIBSS to see if I could apply for a grant from the Honeycombe Legacy to undertake a professional course in expert witness work but this was refused.
97. I carried out some work for the Macfarlane Trust as an OT. I was told that my reports were excellent because, being from an OT perspective, they were comprehensive and holistic, unlike the sketchy reports they usually received from

other professions. I was asked by Martin Harvey, the then Chief Executive of the Macfarlane Trust, to visit a member of the trust's staff, after she had suffered a stroke. Based on my professional opinion, I stated that workplace adaptations could be put into place for the lady to facilitate a graded return to her work. I was given the impression that this was not what they had wanted, and, to my knowledge, the member of staff never did return to work for the trust. Following this report, I was not asked to do any further work for the trust.

98. From a personal perspective I found it very degrading to have to go to the Macfarlane Trust to ask for financial assistance. Part of me felt that nobody owed me anything; I have always worked and did not feel that I should be asking for handouts. However, I have not lived the life I would have, had it not been for Andrew's infections. I have been fortunate enough because I have not lived in poverty as I have a profession. I have therefore been able to support myself; but it has undoubtedly been at a cost to my mental well-being.

99. The Macfarlane Trust did offer some limited services for a period of time. For example, there was a group for widows and grieving parents. I remember attending one of these and a bereaved father telling me that it was okay for me because I could "*get another husband*". It felt as though there was a sort of competitive grieving and I felt that attending the groups became quite stressful rather than supportive.

100. The Macfarlane Trust went from being a paternalistic organisation to a period of being empathetic when Ann Hithersay was in charge and she did try to be helpful. The Trust deteriorated under Martin Harvey who was more concerned about what he could get out of the position for himself rather than anything to do with helping people. It became even worse when Ms Jan Barlow took over as she appeared, not only to be lacking in any empathy, but also positively resentful towards the infected and affected community. As the trust approach changed, I was no longer entitled to anything. I dare not even ask for any help today as I

can't face the processes that have to be gone through only to face rejection. Everything is means tested, which may seem reasonable on the face of it. However, it does not allow for those of us who work hard to earn a living but sometimes lose income because of the stresses we experience. These stresses are the result of what we have lived through, continue to be reminded of, and continue to live with the long-term consequences of.

101. Soon after Andrew died, I had a nightmare about The Haemophilia Society. I felt that they did nothing for us. They did not offer support to the infected/affected community nor did they campaign for justice or for the infected haemophiliacs to receive the care they needed and deserved.

GRO-B

GRO-B

GRO-B

Section 8. Other Issues/Conclusion

109. When Andrew was very poorly in hospital, I used to sit by his bedside watching over him, and I remember thinking and questioning why this suffering was happening to him. I concluded that I could not understand it within this lifetime but maybe there would be another time when it would make sense as part of a bigger picture. I just had to be at peace with this in my thoughts. I am a strong believer in taking comfort from what you can and not worrying about it appearing odd to other people. This might be beliefs about an after-life, wearing your late partner's clothing, developing little rituals or whatever. I truly believe that Andrew was my soulmate. I believe we had an existence together before this life and we will have an existence after this life. Without holding this belief, I would not be able to face living another day.

110. Following the official opening of the Inquiry I felt so unexpectedly overwhelmed with grief that I ended up taking a month off work as I could not concentrate. My brain would not stop bringing up memories of things we had been through and my sleep was disturbed by nightmares. In my employment as a case manager, I have limited sick pay, so my income therefore suffered.

111. One of the reasons the inquiry opening opened up so much grief for me was that, whilst at the opening, I spent time discussing the Treloar boys with GRO-A (who I knew when he was a very young boy at Treloar's). I asked him about a particular boy, who I had not heard of for years. I had hoped he might have been one of the boys who, against the odds, had made it through. GRO-A told me that he had passed away. I found this extremely hard to deal with. I felt unable to process my feelings. The loss of the boys as a community is very difficult to describe.

112. I want justice for Andrew, the rest of the infected haemophiliacs and their families. I want somebody to be held accountable for this tragedy.

Anonymity, disclosure and redaction

113. I do wish not wish to apply for anonymity and I would like 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 10-3-19