

Witness Name: Susan Elizabeth Threakall

Statement No: WITN1564001

Exhibits: WITN1564002-3

Dated: December 2018

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF SUSAN ELIZABETH THREAKALL

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I, Susan Elizabeth Threakall will say as follows:-

#### Section 1. Introduction

1. My name is Susan Elizabeth Threakall. I was born on [GRO-C] 1953 and I live at [GRO-C] Devon, [GRO-C] with my partner.
2. My husband, Robert 'Bob' Threakall, died on 20 February 1991 after being infected with HIV and Hepatitis C via treatment with contaminated blood products.
3. I moved from our family home in Birmingham in December 2001 and have been living in North Devon ever since.
4. This witness statement has been prepared without the benefit of access to my late husband's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

## Section 2. How infected

5. Bob was born on GRO-C 1943 and diagnosed with severe Haemophilia A.
6. Throughout his childhood treatment was limited and often consisted of just bed rest and cold compresses although I understand that on at least one occasion he was prescribed snake venom.
7. When he was 21 years old the use of Cryoprecipitate transformed treatment of his haemophilia. He continued on Cryoprecipitate until 23 October 1977 when he was first given Factor VIII. I attach a copy of Bob's treatment records at **WITN1563002**. I attach a copy of Bob's medical chronology at **WITN1563003**.
8. Bob was treated at the Haemophilia Centre at the Queen Elizabeth Hospital, Birmingham (QEH). His consultants were Dr Ian Franklin and Dr Frank Hill, although he usually saw the former.
9. Bob was not given any advice regarding possible risks before his treatment was changed from Cryoprecipitate to Factor VIII. We had been friends and work colleagues for some time before beginning a relationship and I recall his real reluctance to use treatment at all, even when he was in pain. On one occasion, when I asked him why, he simply replied: 'You don't know what's in it'.
10. In 1981, shortly before we married, Bob was infected with Hepatitis B through his treatment. I recall that he was advised about a suitable diet but at no time was there a conversation about possible long-term damage to his liver, or about the possibility of him passing the infection on to me or others. He was just told that 'this sort of thing' was to be expected following treatment with blood products and that it would be transitory.

11. Bob first tested positive for HIV on 23 January 1985 but wasn't told about it until that summer. Like his Hepatitis B diagnosis, he was informed alone at a regular clinic appointment.
12. On the day that Bob was advised of his HIV status, I was at work. He came and met me at lunchtime and I remember sitting in his car when he told me. He said that he had been told to 'use a condom and tell Sue not to get pregnant for at least two years'. That was it. That was all the guidance we were given. At the time we were trying for a second baby, so this was devastating news on all counts.
13. I am angered by the six month delay in Bob being informed of his HIV status, as this was a delay that could have proved fatal to me, as it did to so many others.
14. Bob was never told that he had Hepatitis C and in fact I only found out a long time after his death, when I noticed a brief post-mortem comment: 'NANBH' (Non-A, Non-B Hepatitis).
15. I can find no reference to his Hepatitis C status anywhere in his notes, even in microbiology. All I can deduce from this is that his notes have been redacted or that his notes are not complete.

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

16. I recall that Bob began to suffer from cold sores (Herpes). On one occasion he was dreadfully upset when I snatched our toddler son away from him when he went to kiss him, as I knew that Herpes is easily passed on and, if contracted, lifelong.

### **Section 4. Consent**

17. Bob was definitely tested without his knowledge. There were clearly test results of some description which indicated he was Non A, Non B (later known

as Hepatitis C) positive, yet we were never informed of either a test or its result.

18. Although I have no hard evidence that Bob was being tested for the purpose of research, I believe he was tested for research because he was tested without consent and we were not advised of the tests done, the purposes of the tests or their results. I also note that on a form that was filled in to notify the UKHCOD following his death there was a question that specifically asked whether there were "...any specimens of serum and/or lymph node or other organs from biopsy or PM available for study...". It is clear to me that haemophiliacs were being used for study although I cannot conclusively say that Bob was one of them.

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

19. The impact of the infections on Bob's life was huge. Initially he had to decide who to tell. We discussed it with his mother and sister, his two oldest boys (Paul and Mark) and our friends. We had to deal with their sympathy and the fact that we were no longer living the same life we had pre-diagnosis. In some ways we became defined by the infections. Bob had to deal with the unknown, the prospect of a horrible illness, dying, and leaving behind those he loved. In short, all his plans and dreams in his newly married life crashed down around him.

20. Our social life remained as it was; centred around family and close friends, but as Bob's illness progressed he struggled to maintain the same level of input and enjoyment. There was always the unspoken feeling that this might be the last birthday/Christmas/holiday etc. Bob's focus gradually shifted from family life to concerns about his health, campaigning etc.

21. Sex became difficult. At the time of his diagnosis we had a normal healthy sex life and we were trying for a second baby. Post diagnosis intimacy became stressful because we were both conscious that Bob did not want to infect me. I was desperate for another child but we decided not to risk it. In

those days there was no sperm-washing and no-one could help us. We were pioneers in this awful territory and we blundered on as best we could.

22. We had been married for less than four years and had lovingly created our home and family. We had good jobs, great friends and were happy. Post diagnosis I felt as if everything we had built was in jeopardy. We were unable to have more children, our sex life was affected, the stress of Bob's increasingly poor health took a dreadful toll on us all, and we had no idea what our future held. Our once hopeful future was now a terrifying abyss of fear.

23. Our life revolved around finding out information about HIV, about AIDS, about possible treatments, and so on. It was a constant thread running alongside our normal day-to-day activities. It never went away. On one occasion, when we were on holiday, I wasn't well and remember the sheer terror that I felt, wondering if I too had contracted HIV. It was always there; a terrible thread running through every day.

24. As Bob became more and more ill he didn't want me to go anywhere or do anything. I think he may have been scared to be alone, but I also think he started to resent the idea that I was off doing something nice whilst he was suffering so much. He no longer had the stamina to do many of the everyday things we used to do together so I had to do what I could to keep things ticking over.

25. On one occasion I signed up for an art session at our local library. It only lasted two or three hours and I loved it, but I recall that Bob was really annoyed that I was away for 'so long'. On another occasion he got cross because I was chatting and joking with the milkman. It was very unlike the Bob I married who wouldn't have been bothered at all. One day I took David to the Black Country Museum. Bob was at work (he wouldn't have been able to cope with the trip anyway at that stage) and I remember he was quite annoyed that we had gone. Our relationship was put under terrible strain. I

did everything I could to help and support him, but I think we both knew what the final outcome was likely to be and we were scared.

26. Bob was a very, very frightened man. Most of the time he dealt with it all stoically, but whenever he wasn't well I could see the terror in his eyes. This was particularly true when he had colds/chest infections, as he was terrified of contracting PCP pneumonia, which he knew was an indication of full-blown AIDS. On one occasion when he was slightly unwell, he got in such a state I am ashamed to say I couldn't cope and went out to a friend's for a couple of hours. He was very concerned that he would die and leave us all; three children without a father and me without a husband.

27. He was also angry – very angry. The more we found out, the more we realised that this had not been an inadvertent accident as we first believed. It could have been prevented. We had no idea in the early days about exactly what went into the treatment, or what its origins were. If Bob had known the truth there is no way he would have agreed to change from Cryoprecipitate to commercial concentrate. He was an intelligent man and was deliberately denied the chance to make an informed choice by those who were supposed to be caring for him.

28. Bob was concerned when he contracted Hepatitis B, but at that point he trusted his doctors and believed them when they said it was transitory. It made him even more wary about the treatment. He had no idea what damage had already been done to his liver.

29. HIV was his biggest concern. Everywhere we looked it was in our faces. I believe the government's 'Don't Die of Ignorance' campaign was a complete disaster for the haemophilic population. People heard 'haemophilia' and automatically associated it with 'AIDS'.

30. The stigma was dreadful and there was no escape from it. Celebrities started dying. Television news showed the dreadful effects on the American gay population, the tombstone adverts were on television every night and leaflets

about AIDS were dropped through the letterbox. The fear and the stigma were with us every morning when we woke up and every night when we went to sleep. In the eyes of the public I suppose it defined us as a family. It became like a cloak that was always around us. We were lucky as, having made an early decision not to hide it and to go public, we found only sympathy and understanding; others were not so fortunate. We often overheard throwaway comments from others when we were out and it was clear that they were afraid. It was a constant reminder that we were one of the families that everyone was talking about.

31. We were thrown into the same category as other AIDS victims, and then had to explain how Bob had been *given* the virus by his doctors. We did publicity for the Haemophilia Society's campaign, going on national television as well as doing a lot of local press, but always we were there alongside crumbling tombstones and being told not to die of ignorance. This had *happened* to us, it was *given* to us, and yet the general perception of the virus involved blame and sanctions.

32. Aside from the psychological effects of his infections, Bob also suffered physically.

33. Following his Hepatitis B infection he became very thin and jaundiced. These visible effects gradually went away after a few weeks but his liver was clearly put under stress; later compounded when, unbeknownst to him, he contracted Hepatitis C.

34. Towards the end of his life it was clear that the doctors were concerned about his liver and spleen which were both enlarged. They discussed performing a liver biopsy (which would have been risky because of Bob's severe haemophilia) but Bob didn't live long enough in any event. I have since wondered why this was considered given that the doctors must have known Bob was dying and that it was such a risky procedure for him. I can only assume that they would have liked a sample for research purposes.

35. By October 1986, within a few years of his first positive HIV test, Bob had developed alarmingly swollen lymph nodes. These were most obvious in his neck. We used to try and make light of it but it was really scary to see, every day, what was happening to him. At times I was able to ignore the internal issues but it was much harder to do that when Bob started to physically change.
36. By April 1987 Bob started to get infections including cystitis, ear infections, throat infections, chest infections. They seemed endless. He never seemed well.
37. By April 1988 he was diagnosed with Persistent Generalised Lymphadenopathy (PGL). He started to have night sweats, fevers and bouts of diarrhoea. By January 1990, a year before he died, his weight loss was recorded in his notes. Bob started to have trouble swallowing, probably because of oral thrush, and he was always, always cold.
38. Bob was able to continue working for the DHSS as an Executive Officer until a few months before his death. He loved his job and wanted to work despite the fact he was so ill. The idea of not working really upset him.
39. Like many haemophiliacs of his generation it was an uphill battle for Bob's parents to secure an education for him. The only school that would take him was a special school several miles from his home. He left with no formal qualifications and went to night school to get the O-levels he needed to join the Civil Service. He was rightly extremely proud of this and deeply resented the impact his health had on his ability to work and provide for his children.
40. His notes record that on 10 January 1991 an X-ray showed 'shadowing on both lungs'. He was never treated for that and died on 20 February 1991.
41. Bob's last few days were a nightmare. He was disorientated, scared and clearly dying, although he didn't know it. He was due to go into hospital on a Monday to have a naso-gastric tube fitted in order to supplement his nutrition



as he was so emaciated, but by the Sunday he was clearly so desperately ill that I phoned the hospital with a view to getting him admitted. He could barely stand and his skin was blue-tinged. He was struggling to breathe and could barely swallow. After a bit of a battle they agreed that I should bring him in.

42. We struggled to get Bob in the car and when we arrived at the hospital I had to track down a wheelchair and wheel him to the ward myself. The doctor admitting him said: *'Well, he doesn't look as bad as you said he was on the phone'*. Within hours, and following an X-ray, I was taken into a room with a few doctors and was shown the resultant film. They explained that he had very little normal lung tissue left because of the extent of the infection in both lungs. I believe they were trying to tell me he was terminal, but I just couldn't grasp it. I found out months later that our GP had already been informed that Bob was terminal but we had no idea. We were not prepared.

43. Bob was put in the care of a Junior Doctor, Dr Rousseau, because Dr Franklin was away in Scotland. She was very young and clearly exhausted. I remember her telling me she had just completed a 72-hour shift and was now covering for someone else. They threw everything at Bob – Erythromycin (which we knew would give him diarrhoea), IV Septrin (in case it was PCP) and even treatment for TB, just in case.

44. On the Sunday night Bob became very confused and agitated. We went to close the curtains and he got very cross as he thought it was daytime. Apparently his electrolyte levels were unbalanced and he was put on a drip which seemed to help.

45. I don't remember going home that day, or how I got there. Apparently a couple of friends came and collected me late at night and I got back somehow the next morning. Those three days just merged into one.

46. Dr Rousseau insisted on ploughing through all the tests that had previously been ordered by Dr Franklin. This included a test for arterial blood gases which meant they had to remove his oxygen mask (set at 100%) whilst blood

was being drawn. It also meant he had to have Factor VIII. Carey Howells, one of the haemophilia nurses who came to administer the Factor VIII, cried and begged Dr Rousseau not to undertake the test. It was obvious from Bob's colour (blue) what the test would show, but she went ahead anyway.

47. At one stage the Erythromycin gave Bob uncontrollable diarrhoea. There were no nurses to help so a friend and I helped him out of bed, on to a commode, and cleaned him up.

48. Dr Rousseau explained that she had never given Septrin by IV before, and she seemed to have a problem understanding the instructions on the accompanying leaflet because English was her second language. She gave me the leaflet and asked me to read it and tell her what side-effects she should look out for. I did as she asked and explained that one of the most serious side-effects was plummeting blood pressure.

49. The Septrin was duly added to Bob's saline drip. It seemed to go ok at first but then the drip ran out. I alerted staff several times to the fact that he was becoming more and more ill and – in my opinion – dehydrated. I even interrupted a handover meeting but he went without fluid for a long time. At some stage my sister and his best friend turned up, as did both of my stepsons. They called for another doctor as – predictably – Bob's blood pressure crashed. The doctor hauled him up the bed and his arms flopped to the sides as if he was being crucified. Then he died. His last lucid words to were: 'Is it sorted?' He meant financially. He meant would we be ok. I lied and said yes, it was fine.

50. His medical notes confirm that he was dehydrated.

51. The next day we asked to view Bob's body in the hospital mortuary. At first the request was refused, on the basis that they couldn't open the body bag he had been put in. Eventually, after the intervention of a family friend, they agreed, but only if we did not unzip the bag past chest level. Someone had put a horrible cardboard ruff round his neck, but he was otherwise untouched

– eyes still open, unwashed, staring out from dead eyes. Again, the nurses cried.

52. Bob's infection also had a huge impact on his family.

53. Bob's mum, Hazel, was fabulous. She was a lovely, intelligent, kind lady who was absolutely devastated by what had happened to her only son. She stayed strong until he died, but passed away a few years afterwards of a brain hemorrhage.

54. Bob's sister was a big part of our family and I loved having a sister-in-law, but she drifted away into a different life after losing her brother and her mum.

55. Paul, Bob's eldest son, was 14 when I married Bob. We got on really well, but he really struggled with his father's illness. He had so much potential and was brilliant with computers; he could have grown up to do anything. However, he struggled with his self-esteem and confidence which stifled his potential and he rushed into a marriage that wasn't right for him shortly after Bob's death. He never achieved the bright future that appeared to be mapped out for him.

56. My second step-son, Mark, viewed me as the step-mother from hell. He took his father's death very, very hard and threatened to drop out of university. I was hard on him and told him that if he dropped out of university he would have to start paying rent at home. I only did this because I knew that Bob really wanted Mark to succeed at university. He went back and completed his degree. He has since stayed in Brighton and made it clear that he doesn't really want anything to do with our dysfunctional family. One of the last things that Bob asked me to do was to look after the boys. I tried my best but I am deeply saddened by how things turned out.

57. I had one son with Bob before he died. David was only 7 when his father passed away. David appeared to initially cope reasonably well, however, despite passing his 11+ exam and going to grammar school, he struggled academically.

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58.

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59. It is a tragedy that all three of Bob's highly intelligent boys, who were on course to do very well, have ultimately under-achieved.

60. Personally, I had to leave my job as a Deputy Head Teacher as it became impossible to juggle my career and my husband. Bob was increasingly unwell and we were struggling. I took up supply work so that I could work around Bob's health, and with no extra responsibilities. It was hard, and I missed my previous role, which I adored and I believed I was good at.

61. Following Bob's death I was a mess. Before, I was able to handle a whole hall full of children with no problems but after his death I struggled to cope with one class. I left a short-term contract early after completely breaking down at the end of the drive. I just wanted to be at home. Money became an issue and I was out of my depth as Bob had handled all the finances. I never returned to full-time teaching and the most I ever achieved was a years' part-time contract.

62. When I was in my 40s my GP said he would support an application to retire early on health grounds (with full pension rights), but to me that felt like

cheating, so I struggled on. Over the years I did care work, worked in a Post Office, had two ward clerk jobs, taught foreign students, and did home tuition. Eventually I took early retirement at aged 50, but my pension – which should have been substantial – is tiny.

63. I ended up deeply in debt and there are charges on my property (including from the MacFarlane Trust which I believe has now been 'sold on' to the Terence Higgins Trust). I am currently investigating taking out an Equity Release in order to keep a roof above my head. I am nearly 66 and should be enjoying a financially secure retirement, yet I struggle daily to pay the bills. Pretty much every decision I make is governed by me thinking 'Can I afford it?'

64. My health has really suffered. In the last few years I have had a hysterectomy, a knee replacement, a hip replacement and – this year – breast cancer. I am convinced this is partly due to stress. I have excruciatingly painful arthritis and would really like to do gentle gym work and swimming, but simply can't afford it. My health is poor and I can't afford to improve it.

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

65. I don't think Bob had trouble actually obtaining treatment, because in those days there really wasn't any treatment except for AZT. I do feel though, that because he was attending a haemophilia clinic in a haematology unit, he lacked any specialist HIV care. This particularly impacted towards the end of his life when despite a chest X-ray showing shadowing on both lungs some weeks before his death, there was no active treatment until three days before he died.

66. Initially there was no counselling available at the QEH, so following Bob's HIV diagnosis we were very much left to our own devices. Because we wanted to know what the risks were of trying for another baby, we approached the Oxford Haemophilia Centre. They saw us together and we met their two counsellors, Mary Fletcher and I think another Mary. They subsequently

visited us at home. Eventually Shirley Mallon was appointed in the role of social worker, followed by a gentleman called Andrew. This was in the very early days of HIV and AIDS, and we were all fumbling our way through, with the haemophiliacs being used as guinea pigs for every new initiative or treatment.

67. Three or four years ago the government allocated a sum of money to the Hepatitis C Trust for counselling and I applied for myself and David. We were told that they had run out of funding. It took a lot for us to admit we needed help and I haven't bothered since. Even if the request had been granted I understand they would only have funded a limited number of sessions which is completely inappropriate. Essentially, the psychological support and counselling on offer has been abysmal; completely inadequate and inappropriate. Indeed, rather than being treated with compassion and understanding we have, as a group, been subjected to cruel and callous treatment by those who were responsible and those put in roles to help us.

### **Section 7. Financial Assistance**

68. I believe we were first informed of the possibility of financial support by the Haemophilia Society.

69. When the MacFarlane Trust was set up we were initially awarded an annual holiday grant, which was very much appreciated. We could, if I recall correctly, apply for small grants for health-related issues. We occasionally had a phone call from Ann Hithersay to check how we were, and this continued for some time after Bob's death, before the organisation deteriorated to the cruel, humiliating support system that it remains today.

70. In the early days it was very simple; I don't remember much beyond phone calls. There was never a problem, partly because we were both working and had a good income anyway, so any support was seen as a bonus and not an essential income.

71. In the months following Bob's death I had some help from the MacFarlane Trust, such as a funeral grant. However, it soon became evident that as I started to struggle financially, the Trust became more prescriptive, less kind and less willing to help. I had lost both of our incomes and was flailing around.

72. The Trust paid for Susan Daniels, a financial advisor, to come and help me re-mortgage which helped for a while. I eked out the last £10,000 of the 1991 settlement for several years. The rest of it was awarded by the courts to the three boys and used on Bob's 'shopping list' of what he wanted to do with it. I never felt it was mine and I simply spent it as he wished. Indeed, it has been a fundamental problem that, apart from the £10,000 one-off payment, no money has ever been paid to widows in their own right and I have therefore always felt that I have to spend any money received as Bob would have wanted because it has not felt like my money at all.

73. In 2001 I moved to Devon with my present partner to run a small sub post office. Following this move I received a letter from GRO-D of the MacFarlane Trust, which started 'when you move to Devon with your new partner, leaving your son behind in Birmingham', which made me extremely angry. In fact I read it and burst into tears as it completely misrepresented both the events and my relationship with David.

74. When we got to Devon, the cottage/post office we moved to was virtually falling down and it cost me every penny I had, plus every credit card I could get my hands on, to make it habitable. I did various jobs and was just about holding my head above water when I started to have health problems. I remember one evening calling Martin Harvey from my car in the car park of the hospital where I was working, and ended up almost hysterical as I told him that the car needed over £300-worth of work to get it through the MOT and without a car I couldn't get to work. I remember going through pockets, bags and drawers and getting together 50p to use for enough petrol to get me home one night – fortunately only a few miles. I remember wearing the wrong prescription glasses for 18 months, and suffering horrible headaches as a

result, because the trustees over-ruled Martin Harvey who said they would pay for new glasses. I was told by a trustee of the MacFarlane Trust that as soon as they realised a grant request was from me, it was turned down on principle. I also recall being told that the MacFarlane Trust had given me more help than any other widow. I then learnt that I wasn't the only one to have been told this!

75. The utter desperation people face when applying for grants is shameful. The humiliation and embarrassment is unacceptable. Widows, in particular, have been deliberately and knowingly deprived of support. Their grant options have become less and less over the years. With the inception of the EIBSS we are entitled to little more than a funeral grant and re-training for a new career – a joke when most of us are in our 50s and 60s.

76. We have been deliberately kept at just above the poverty level and they insist on taking household income into account, even wanting to know our partners' National Insurance numbers. They never consider our outgoings. We are treated like scroungers. To offer only 'support' to a group of people who have been so greatly harmed by the state is unfathomable.

77. The final straw for English widows is the huge difference between the payments offered here and those in Scotland. We are entitled to nothing other than a discretionary top-up, yet in Scotland a widow of someone co-infected like Bob gets an annual pension-type payment of £27,750. That money would transform my life and yet every day for me is a miserable struggle beginning with me checking my bank balance. It is my belief that the government has done everything it can (a) to keep us struggling and therefore unable to challenge them legally, and (b) to portray us as grasping scroungers. I despise them.

78. In the past I have had a grant for a new laptop, yet when that one reached the end of its life they refused to pay for another. They have paid for Susan Daniels support in the past, yet do not do that now, as far as I know. Most of my grant requests have been for my son, David, for things like setting up in a



new flat, a rent deposit and so on. The MacFarlane Trust payed for the services of Neil Bateman, the benefits advisor to help David, and yet the EIBSS have refused to continue this support, so I have had to pay him privately which has simply put me further into debt. A few days before Christmas I received his final bill; this was for over £400. I only had about £100 in my account at the time and that had to last me two weeks. I have a hole in my roof, wallpaper peeling off the walls in the bedroom, a rotten window frame in the bathroom and the glass is falling out of one of my windows. My car desperately needs a service and the brakes need attention. I can't afford to have any of these things looked at/fixed. Fortunately Neil has agreed to let pay his bill in instalments.

79. In May this year I was diagnosed with breast cancer. My treatment involved surgery and radiotherapy. For the radiotherapy I had to travel to Exeter five days a week, for three weeks – a 120 mile round-trip each day. I asked for help with travelling costs and the EIBSS refused. I asked for a respite grant for a short break after treatment and they refused that too, on the basis that they *'don't give respite grants to widows'*.

80. The EIBSS system appears to be designed to stop people applying – it has quickly been nicknamed the 'last chance saloon' as people have to first prove they have tried every other avenue for support, and if necessary provide several quotes - and even then people get turned down.

81. I applied for a grant from the MacFarlane Trust a few years ago, at a time when our Post Office business had been closed down by the government and I was very poorly, and they refused. They did, however, give me a loan, secured against my home. They wanted over £300 per month in repayment! We eventually agreed on £25, which they deducted at source from my top-up payment. I now longer pay this as my top-up payment was stopped by the EIBSS when I was too ill to fill in the form and sort out all the evidence that they required during my cancer treatment. I have not re-applied as I simply can't face it anymore.

82. The support scheme is, and always has been, inadequate. It does not replace the financial independence that most of us knew before this happened to us. No assessment has ever been done on the impact of contaminated blood on the haemophilia community, and likewise there has been no assessment of need, so any payments are based entirely on what the government deem us to deserve. Likewise, the discretionary grant system is at best a disgrace, and at worst deranged; for example they have a policy of not paying for white goods – why not? I know of one haemophiliac who went for 18 months without a fridge! Contaminated blood took away our lives as we knew them and replaced them with a tortuous existence.

83. I resist feeling happy. Time has taught me that just when you think things are going well, your world can come crashing down in an instant. This happens in the campaign as well - you think you're nearing the end and it might be all over soon, then the government plays another crafty trick that keeps us all dangling on strings. More than that, though, I resist letting people know when I do nice things. My sister often asks why I rarely put holiday photos on Facebook...it's partly common sense but also the fact that I don't want to advertise I've had a holiday/been to the theatre/had a meal out (even though these things are usually funded at least partly by others) because I'm afraid that if government see my posts they will think I don't need any more financial help. In short, I'm afraid to relax and live as normal a life as I can in case it's misunderstood, and yet the life I live is a million miles away in terms of affordability, than the one I should be in. I should be able to save, have holidays, wear nice clothes and go out when I want to. I should not have been left in a position where I constantly have to make choices, based on money.

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

84. I have been involved with the support group Tainted Blood from the outset. It is like an unpaid, full-time job, and I put a lot of time and energy into helping our community and fighting for justice. With all of the hours I have put into this, including a lot of time investigating the situation in Ireland and Scotland, I

have a lot more information that does not fall within the remit of the Rule 9 Request provided by the Inquiry.

85. David has often said that he lost two parents as a result of this scandal – Bob to his infection and me to the campaign.

86. Pursuant to paragraph 2.9 of the Notice of Determination in the Award made to my Solicitors preparation of this statement does not cover investigative work. I would like to give evidence on the matters set out above and I am unable to do so in this statement.

#### Anonymity, Disclosure and Redaction

87. I confirm that I do not wish to apply for anonymity and I understand that this statement will be published and disclosed as part of the Inquiry.

88. I would like to be called to give oral evidence at the Inquiry.

#### Statement of Truth

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

Signed.....

GRO-C

Dated .....

28/12/2018