Witness Name: Violet Slater

Statement No.: WITN3391001

Exhibits: Nil

Dated: As August 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF VIOLET SLATER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 7 June 2019.

I, Violet Slater, will say as follows: -

Section 1. Introduction

1. My name is Nellie Violet Slater but I am known as Violet Slater. My date of birth is GRO-C 1952 and my address is known to the Inquiry. I am retired and live in Scotland with my husband, who is a haemophiliac and contracted Hepatitis C from infected blood products. My husband, Malcolm Slater (W0599), has given a separate witness statement to the Inquiry. I intend to speak about my husband, in particular, the nature of his illness, how the illness affected us, the treatment received and the impact it had on our lives together.

Section 2. Malcolm's infection with Hepatitis C

- 2. I married Malcolm in 1980. He has haemophilia A. We first lived in Surrey, then moved to Cirencester in late 1980. Before we married, Malcolm was really healthy. He would go horse-riding all the time on Frensham Common with his colleague's husband. I remember thinking, "Haemophilia isn't so bad, he's fine!"
- 3. We got married and he was still fine. When we lived in Cirencester after we got married, he seemed to be in a good phase in his life. I don't recall him even having bleeds then. We walked our dog a lot, and Malcolm used to ride horses with my colleague Susie, who was a three-day eventer.
- 4. He would go and ride her horses at the weekend; I joined in and they soon discovered not all Irish people knew how to ride a horse! We explored the Cotswolds, and life was fine, Malcolm was fitter then I remember he once dug us out when we were snowed in and with neighbours helped to get access to the end of our road where a busload of people were trapped in the snow.
- 5. We were living in Cirencester when for some reason it was decided by the GP that Malcolm should have his varicose veins operated on, in case he should knock them and have a bleed. Malcolm was under the care of the Churchill Hospital in Oxford for his haemophilia.
- 6. He went to the Ackland Hospital in Oxford for the operation in late 1982; he had private health insurance through his work so it all happened really quickly. This was the first time I was worried, he was going to have an operation. It was my first real experience of life with a

haemophiliac – up until then he had lived like a normal person. He had Factor VIII cover before and after the operation, provided by the Churchill Hospital.

- 7. I couldn't drive then, I was too scared of the traffic in England and I had never owned a car, so Susie drove me over to Oxford. Malcolm was fine, he came home and all went well so we thought. Malcolm would never have time off work for haemophilia; he said he needed to give total commitment to his job, he had to be seen to be healthier than every other guy and prove it wasn't an impediment to his work. So he would have gone back to work as early as possible if another person took two weeks off, Malcolm would only take three days. He would have gone back to work limping.
- 8. He did become sick; I can't remember exactly when, but we think it was late 1981 or early 1982 as he got sick before the testing started. This is one of the times when I think I blotted out a lot of it. I remember him being sick, vomiting and diarrhoea, losing weight. I remember him being confused. But I didn't worry that much about it; I was concerned, but I wasn't as concerned as I should have been with the benefit of hindsight.
- 9. When Malcolm first got sick we were told he had hepatitis or jaundice, but we didn't know it was hepatitis C (or NANB) at the time, and we didn't know it was anything to do with blood. We had been abroad on holiday to Tunisia and they said it was probably something he had got on holiday, even though we had eaten pretty much the same things and I wasn't infected. He had tummy upset in Tunisia but had recovered long before his operation at the Ackland.
- 10. It was first referred to as non-A non-B Hepatitis in early to mid-1983, after the newspaper headlines had emerged. We were not given any

advice for looking after ourselves with the hepatitis; just what sort of things to avoid eating and to avoid alcohol. I knew that already, and Malcolm wasn't eating much anyway. We didn't think hepatitis was too bad at that point.

- 11. I had previously worked in the NHS as a cook and I had encountered people with hepatitis before. I used to work with the hospital dietician and patients who were ill, to devise menus for them which would be suitable for their illness. So I just thought that I had to sort his diet out and he would get better. I thought I could play that role. I went back to what I had learned, eliminating cheese, fats, not giving him meat (which he was happy about!), and buying lots of fish. And then he said he'd just like vegetables and wanted to be vegetarian.
- 12. But changing his diet didn't work. I recall that some days he wouldn't be sick, but he would be really nauseated; and other times he would be really sick. I thought it was quite bad, what he had, but I still thought that I had never known anybody that had died from it, so he would be OK soon. I have always been able to take life a day at a time when things go wrong, and I have always used that mentality throughout the years we will see what today brings and not worry about tomorrow too much. Maybe this was the first time I did that.
- 13. Malcolm's hepatitis was recurring. He would get better for a bit, then go downhill again. This continued for months. I note that Dr Trowell wrote on 11 June 1982 that in many ways he had made a good recovery but results implied a minor relapse. He remained exhausted and had joint pain; I don't think Malcolm ever fully recovered before he had another bout of hepatitis some years later in York.

Section 3. Laboratory testing

- 14. In very early 1983 I became pregnant and we were happy about it; Malcolm suggested that we should talk to the doctors at Oxford because he was a haemophiliac, to see whether there were any implications for us. I thought this was a good idea, so we went to see Dr Rizza, who seemed very nice.
- 15. I wanted to know if there were any concerns; one of my concerns was whether I would have a child who might be a carrier for haemophilia. No one had ever told us we could have a child who had haemophilia. In fact, our daughter Bryony went through her entire childhood without us knowing that she had an inherited bleeding disorder. When at primary school, she came home one day and asked me to put a big plaster on the back of her leg. She told me she had been taken out of class that day and several teachers and the headmistress had questioned her about the large bruise high up on her thigh.
- 16. She insisted she did not know what had happened to cause this. I was alarmed and took her to the GP. He knew her well as his son and Bryony were classmates and she went to their house. I asked him to speak to her alone and try to find out what had happened (before the Social workers came calling!) She could not tell him. He said he would deal with any questions which came from the school and not to worry. Years later she had her wisdom teeth out and had a bleed.
- 17.I recall Dr Rizza being incredibly reassuring. He said we didn't have to worry about that because there was something to do with the potential for transplanting the missing chromosome or gene in the not too distant future, probably within 10 years or so. So by the time our child would be old enough to want children of their own, haemophilia wouldn't be a problem anymore. The message was that there was nothing to worry

about, enjoy your pregnancy and baby and have a good life. I went away really happy. I was maybe 8 weeks pregnant then, so February 1983.

- 18. Not long after this, laboratory staff from the Churchill Hospital in Oxford started arriving at our home in Cirencester to test our blood. I was pregnant with our son at the time. I know that it started at an early stage in my pregnancy our son was due in GRO-C 1983, so this would have been early 1983. It was definitely after we had visited Dr Rizza; they knew I was pregnant at Oxford.
- 19.I don't remember being contacted by them; I think they must have phoned Malcolm. They wouldn't have just turned up on the doorstep, they asked to come to our house that was their suggestion. I remember thinking it was really weird. I was really sick when I was pregnant with our son and I wasn't happy that they were coming I was working all week, I was tired, and Malcolm was ill. He thinks he may have been off work when they started coming. Straight away I was aware that they wanted to see me and take my blood as well as Malcolm's.
- 20. They would come in the evening after work, about 7pm. I wonder if this was because I would have refused to take time off work, as my company would not have been supportive. I never used to go to the Churchill with Malcolm because I wouldn't have dared ask for a day off. We would get home from work and then rush to get something to eat before they arrived.
- 21. The people who visited us weren't doctors. They were lab staff and said they were from a research team. They told us they would take blood from both of us. They explained that they wanted us "to be part of

important research and it would be very helpful to the haemophilia community for us to participate".

- 22.I couldn't understand the 'us'. Why us? I wasn't a haemophiliac. That was never explained to me. I thought I'd let them have my blood once; I didn't see why they wanted it, but they could have it. We were both concerned that they wanted my blood as well, that was the biggest concern. At that stage we were given no explanation of what the research was or why we were included in it. We thought it was to do with haemophilia but that is about all we knew.
- 23. When we pressed them as to what the research project was, they were not forthcoming. It was a mystery that we talked about. We asked and they avoided it. They would just say, "You are doing such a good thing. This could help your future." It must have been an expensive project the Churchill treated haemophiliacs from across the country, and they were going to other people's homes, not just us. Malcolm learned this in discussion with them. It must have taken them at least an hour to get to us from Oxford.
- 24. A man and a woman would visit us, and they would come to the house in normal clothes. Once inside, they would put on protective clothes. They wore plastic all-in-one boiler suits that covered their head, and they put on gloves and protective glasses. I don't recall them having anything to cover their mouth and nose. And I thought, they're only taking a blood test, what is this all about? It was the weirdest thing the doctor doesn't do that.
- 25. They stood in our living room and took our blood. They would take several vials of blood at one time. We were concerned what the neighbours would think. We had large tall windows. I remember us

- saying it was like a crime scene on television! We were very puzzled and concerned; it's the strangest thing that ever happened to me.
- 26. They would stay for about half an hour and would chat with us, they didn't just take blood and go. They would ask about our health, asking probing questions about both of our general health, and it was all noted down. They made records. It was a usual set of questions each time.
- 27. They said they would come back in a couple of weeks. I was irritated by it. I said to Malcolm, "We go to work and we come home and then these people arrive just tell them we don't want to be part of this research." He said we should go along with it; it was obviously something important, and if it benefitted him and other people in the long run then we should do it.
- 28. They didn't come to the house many times; I think I said to them that enough was enough, I wouldn't do this anymore if they were doing haemophilia tests they didn't need me. I think they took my blood on three occasions, but after I refused, they continued to see Malcolm and take his blood at his workplace, as they could see him during the day there. He would book out the medical room at work and a woman would visit him to take his blood. Once inside the medical room she would put the protective clothing on, including eye cover she wouldn't wear it in the office, it would have set tongues wagging. They visited Malcolm at work for months.
- 29. The gaps between visits got longer and longer, and eventually they stopped. All through this Malcolm was still going to the Churchill Hospital for his haemophilia. He took me on very few occasions as I was still working. We never talked much about Malcolm having haemophilia, it was just there. I never went to the Churchill with him unless there was a specific reason to.

- 30. At some point in the first half of 1983, after the testing had started and whilst I was still pregnant, I decided to go shopping in Waitrose on a particular Sunday to get some sausages. We always read the Sunday Times, so I thought I'd get a paper. I scanned the papers to see what the most interesting news was, and there was a headline: "Haemophiliacs infected with deadly virus". I felt sick. I remember my knees going. I thought that's what they're testing us for we have got something.
- 31.I didn't go shopping at all. I grabbed numerous papers and set off home. I was reading them as I walked home. It was a terrible day. We knew. We were certain that is what they were testing us for. I don't think the papers mentioned hepatitis C it was all about HIV. I thought we've got it, they must think we have it.
- 32. It was a Sunday so there was no doctor around to speak to. I'm sure Malcolm must have phoned the next day. Very soon afterwards we were asked to go to a meeting at the Churchill in Oxford. I recall that our phone call pre-empted the appointment.
- 33. We went there and it was a bad visit. The whole thing was explained in great detail. There were three doctors there; Dr Rizza, maybe Dr Trowell, and a woman was there too. They didn't really mince their words. Malcolm had received blood that they believed could be infected with HIV. They were talking about HIV, not hepatitis C. They said almost everybody had got it Malcolm had been the exception to the rule amongst all the people who received those blood products and then there was talk about him being part of some research as to why he was not testing positive for the virus, that it could be helpful in finding some way of preventing HIV from being passed on. It was some research project into how come Malcolm hadn't got HIV.

- 34. At that meeting, there was no confirmation given that Malcolm had been infected with anything. They told us that they couldn't be certain because testing was not yet adequate. They could test for one strain, but new strains kept appearing in the early stages. There were different strains of HIV and testing was still being developed, so they would have to continue testing us until they were certain. I can't recall whether or not they spoke about hepatitis in that meeting; I think I was traumatised by reading the papers as the only thing in my mind was HIV, although back then they used the term AIDS.
- 35. After that meeting they tested Malcolm regularly at the clinic. They didn't come to the house anymore. Malcolm didn't know why they kept testing him; he didn't trust what they were telling him, but he let them have the blood samples because he had been reliant on the NHS. We were so worried at that stage we worried whether Malcolm was going to die, I was going to die, the baby was going to die, or would some of us die and others be left behind?
- 36. The whole thing happened in such a short space of time. It was sometime between February 1983 and end of July 1983 that the testing, reading the newspapers and going to the Churchill and being given that news happened. I know this because we moved house in late summer 1983 and it all happened before then.
- 37.I feel quite angry because the timeline for all of this wasn't very long. They made no attempt to tell us, we asked before we were told. There were three people potentially affected by this: Malcolm, me, and our baby. I wonder whether they had no clue at that stage, or if they knew and were just under orders not to tell people. How could Dr Rizza give me such assurances, when only months later, HIV was all over the newspapers?

- 38.I now wonder if the reason they were testing my blood was because I was pregnant. I had never made the connection until now, I just wondered why at the time.
- 39. When I was pregnant with our son, they wrote at the top of my pregnancy card "Married to a haemophiliac" in red. I didn't notice any difference in treatment because of that I don't ever recall nurses or any doctor wearing gloves or anything. Nobody else wore all this protective regalia when they came near me, except for the staff from the Churchill who came to test our blood.

Section 4. Yorkshire

- 40. In 1984 we were living in Yorkshire. This was when Malcolm was at his most ill. He was working really long hours and commuting. Our son was about a year old, so it was late 1984. It was very snowy one day and I remember being worried about Malcolm coming home in the snow. He came home and said he wasn't feeling good at all; he felt awful and didn't want to eat. I think he went upstairs to change, then came back down to the sitting room.
- 41. I remember saying he looked terrible, he really looked ill. He had beads of sweat, was grey, and looked really ill. I said I was phoning the doctor there was no point asking Malcolm if he wanted a doctor, he would always say no. So I just said I was phoning him. The doctor wasn't sure he could get to us because there was 3ft of snow; he would try but would also call an ambulance. I think a farmer helped him to get to our home.
- 42. The doctor got there before the ambulance and Malcolm was on the floor by then. He had collapsed. The doctor didn't know what to make

of him but thought it was his heart. I remember him injecting adrenaline into him and waiting for the ambulance, monitoring him really closely. I thought he was going to die before he got to hospital – he was getting worse and worse so quickly.

- 43. I couldn't go with him to the hospital we had only lived in the village a short time and there was no one I could ask to look after my child that night. The vicar in the village heard that Malcolm had been taken to hospital; he and his wife would look after our son whilst I visited Malcolm, and he arranged for parishioners to take me to hospital everyday to visit him.
- 44. The next day I visited him; they had put him in coronary care and said they were expecting him to have a heart attack; a coronary was imminent. They said it was very strange he had all the symptoms but the event hadn't happened.
- 45. We had a lovely consultant haematologist called Cedric Wyllie. He came to see me every day when I came to the hospital to visit Malcolm. One day, he had left a message with a nurse to take me into a room and he would come to see me. He said to me that something had changed that day and they were pretty sure it wasn't his heart now. It had been a horribly worrying time as they had been talking about transferring him to a heart hospital in Leeds for an operation. Dr Wyllie said, "I think he has hepatitis. He's gone yellow."
- 46.I thought that was fantastic! He would get better from that, we could get that sorted. It seemed to me, at that time, to be the lesser of two evils. Dr Wyllie said I was being a bit too optimistic; this was still very serious and he was still really not well. He said not to think of it as that he would be home tomorrow and be fine it wouldn't be like that. Dr Wyllie was the person who explained more about hepatitis to us than

anyone else. This was when we properly knew that Malcolm had hepatitis. He may have known he had hepatitis before, but this was when we knew it was really bad.

47.I don't recall precisely when we were told that Malcolm had non-A, non-B hepatitis. I'm sure I had decided that hepatitis was OK, he would get better – it was HIV that would kill us and we didn't have HIV so it wasn't too bad.

Section 5. Impact

- 48. Malcolm's infection with Hepatitis C through blood products has had an enormous impact on our lives.
- 49. When we were living in Cirencester and the newspapers started reporting about haemophiliacs contracting a deadly virus through blood products, Malcolm started to get questions at work about it. I didn't tell people about his haemophilia, so I wasn't asked any questions. My friend Susie knew, but during that time I didn't see her anymore for other reasons. She was probably the only person in my circle who knew I didn't really have a circle of friends, we had only been in the area a short time.
- 50. From that point on I never told anyone. We would read things in the paper, people were having things painted on their houses; people wouldn't associate with you in case they caught something from a cup or toilet etc. I didn't even tell my family in Ireland what had happened. I didn't think they would understand. I didn't think my parents would cope with it.

- 51. This continued for a long time, we didn't let it be known any more than necessary. Malcolm told some people at work as he felt under a moral duty to do so, but they would have known he was a haemophiliac anyway, so he had to say something. It was different for me; I didn't have to say anything. I wasn't going to take my baby to a mother and toddler group and say that we might have HIV.
- 52. It also had a significant impact on our decision whether to have more children. We weren't convinced until 1986 or 1987 that it was safe to have another child. I had become pregnant soon after our son was born in 1983 but I miscarried; in a way, that was probably a relief to some extent, because we were still facing the unknown. That wasn't how I felt deep down though I wanted to be pregnant, it was very difficult for me.
- 53. At one point I was convinced I was pregnant, but I kept testing as not pregnant; the doctor said that I wanted to be pregnant so much that my body was mimicking the symptoms. He said to go away, have a little bereavement, and that I would be fine.
- 54. After that I didn't want to go to the mother and baby group; someone was always pregnant or there were new babies I avoided pregnant people for four years or so, until I became pregnant with our daughter.
- 55. We had our daughter in August 1988. At this time, we were living in Rutland and our GP lived nearby. We were friendly with him, our children would play together and visit each other's houses. When I got pregnant with our daughter, the GP really wanted me to go for an amniocentesis, where they take cells from the fluid surrounding the baby. He thought I should have that done because Malcolm was a haemophiliac.

- 56. I didn't want to have an amniocentesis because there was a risk of it causing miscarriage and I had miscarried twice previously. But he was really quite persistent and kept asking me. On the very last day that I could possibly have the test, he phoned me up and said I should rethink my decision. He had already spoken to the consultant, who would personally perform the amniocentesis test, and that he didn't think anything would go wrong. He offered to arrange it this afternoon if I wanted.
- 57. The amniocentesis was a test to decide if there was any problem with the baby and I could have a termination if there was, but I had no intention of terminating my pregnancy. The GP then said that it would be reassuring; the test could confirm that everything was fine, I could go through the rest of my pregnancy knowing that everything was fine. So I backed down and had the test. We waited several weeks for the results and everything showed as being fine. But it turned out later that I had been pregnant with twins and one of the babies had miscarried.
- 58. To this day I have never worked out why the GP was so pushy about me having that test and why he went to the trouble of talking to a consultant before I even agreed to it. Did they want to check if I was carrying a baby infected with something? I never gave it a lot of thought until now.
- 59. When the children were young, I was very much a single parent with a husband who provided for us. Malcolm was never well enough to go out to the park with the kids, or go out and do things. He recovered from the hepatitis it had been more severe, but I don't think the effects of the sickness had been as long lasting as the first time but by this point he was having an awful lot of joint pain and other pain, which has continued for the rest of his life.

- 60. Because he was in pain he would often say, "I don't seem to have achieved a lot of work this week." He would work all weekend to make up for the times when he felt he hadn't been up to it at work during the week. He felt it was really, really important to keep his career going and keep on top of things. He thought it would be difficult for him to get another job with his medical track record. He would work 7 days a week when the children were small. He would stay in bed until 11am on a Saturday because he was so wiped out. I gave up on asking him to do things; he just went to work and existed. Life was all about trying to use his free time to try and keep up with work.
- 61. Then we moved to Scotland and that got even worse. He was under a lot more pressure in Scotland. I could see him get more and more ill. He didn't get hepatitis again, and he wasn't too troubled with haemophilia; he didn't have a lot of bleeds, but he was on a treadmill of suffering with awful headaches, migraines all the time, pain all the time, joints raised and very swollen, he couldn't concentrate a lot of the time. At his point, sometime in the mid-1990s his consultants at Edinburgh Royal Infirmary had begun to talk about him having treatment with interferon. At some point during their investigations prior to treatment Malcolm's Hepatitis C cleared. How lucky, we now know.
- 62. Sometimes he would have to write with his left hand. For a long time they said he didn't have arthritis but he had all the symptoms of it. He was on a treadmill of trying to keep going and keep working, and I could see it was beginning to cause a huge amount of stress. He fobbed it off and said he had to do his work. I just raised the children myself.
- 63. Malcolm was getting more and more stressed and I was worried. He was staying later at work at one stage I wondered if he was having an

affair with someone at work, but it just wasn't his style and I didn't think he would have the energy!

- 64. Then it went horribly wrong. For about a week he would set off for work and then come back half an hour later. I think this was in 1995. He would say, "I can't go to work." He couldn't explain why. By the end of the week, I said "we were going to the doctors you don't just not go to work". He was diagnosed with clinical depression. The doctors said it was common with people who had multiple illnesses; it just drains you physically. There was also an unusually high percentage of people at his workplace who had burned out. Malcolm just burned out.
- 65. That was a terrible time. Malcolm doesn't really remember much of it; he blanked it out. He sat on the couch with his head in his hands for months, except for the times when he barricaded himself in the room because he felt he was a threat to us. He barricaded the furniture against the door. The doctor put it down to someone changing his medication. Someone had taken him off medication that he should have been weaned off, so he was hallucinating and seeing things. I had quite a battle; he didn't go out the door for four months.
- 66. It was a struggle even to go to the doctors; I had to take him every time like a child. He didn't want to go, and he felt he mustn't drive. So we bought a dog; I thought to myself that he would never neglect a dog, if the dog needed to go out, he would take it out. And it did the trick. But Malcolm could never go back to work again; he couldn't face the pressure again. His memory had been badly affected; he felt it would be dangerous to work as a lawyer again.
- 67. It was a hugely worrying time. We moved our son to a private school because he had been really badly bullied at his old school, and I thought how are we going to pay for this? I worried. At the time, I

didn't know if Malcolm would have to leave work, if we would get any money, what we would live on. I worked part-time two days a week during term-time, working for community education. It was a big financial worry, as well as Malcolm being ill.

- 68. Around that time, Malcolm's company was having a takeover, and they said that he had to come in and interview head-to-head against another candidate. He would have to travel to Manchester and have interviews over several days. But the doctor said Malcolm was too ill to go to Manchester, never mind have any interviews. So Malcolm said he couldn't go to interview, and his company said that the job would go to the other candidate, simple as that.
- 69. Then they said that he had better come in and talk to them about the future but he said he couldn't go, so I had to. I went in and sat with HR, lawyers and all these people, and made the decisions for Malcolm. I remember that they said he could retire on grounds of ill health and be on two-thirds' salary for the rest of his working life (until he retired and took his pension), but that they would check him every six months, and that if he was found fit to do a job any job, even be a lollipop man that payment would stop totally; or he could just retire with eight years' pension from that company, and they offered another five years on top.
- 70. So I thought, "I don't have any choice. How am I to know he won't get better?" It was enough, we would be OK, and our son would finish his school. So we took the second option. Malcolm did not want to be permanently retired and hoped that one day he would be well enough to do a less demanding job, but he has never been able to work again. He tried voluntary work with CAB but had to give up after a few months.

- 71.I protected the children hugely throughout all of Malcolm's illnesses. We only recently told them details of what had happened, such as the laboratory staff turning up to test our blood. They were totally shocked.
- 72. One of the biggest impacts of all of this has been that, since contracting hepatitis C, Malcolm has refused to consider having Factor VIII. He does not trust it to this day. He will have sometimes, e.g.in recent years for dental work, but he typically tries to refuse it.
- 73. When we lived in Yorkshire, Malcolm fell down the stairs one day and put his head through the wall. He refused Factor VIII. I bumped into the nurse in the village and told her what had happened, and that he wouldn't have Factor VIII. She said he had to have it; I told her that he would probably rather die of a head injury than have it. I was furious with him because he didn't want to have it I understood why he didn't want it, but this time he really needed to reconsider. Malcolm just kept saying to me that he would lie down, check his eyes etc. I got home, told him he had to go to York District Hospital, and that if he didn't go, I would phone them and tell them what had happened.
- 74. We went to see Cedric Wyllie and he sent Malcolm for a scan and said that Malcolm needed Factor VIII. Malcolm said he didn't want to have it. We really trusted Dr Wyllie; everything he said and did, he did totally with Malcolm's interests. And he said, "If you were my son, I would be telling you that you have to have it." So Malcolm relented. This was before he became really ill, so it may be why he got the hepatitis again but I still think it was probably the right thing to do, there wasn't really an option.
- 75. His refusal to have Factor VIII continues. He will take Factor VIII now, but by way of example, just before the investigators interviewed me for this statement, he had been showing me a lump on his stomach for

weeks. He now thinks it was actually a bleed, as it has gone away. All that time he had Factor VIII sitting in the fridge but he still didn't take it.

- 76. It caused a lot of distrust at the time in doctors. It was more a case of what weren't they telling us, than what they had told us. You don't go through that experience the reading the newspaper, knowing they knew, knowing they were giving the factor products it caused distrust.
- 77. For this statement, I have been thinking about the impact that this has had on me. When I had our son, we had been through a terrible year. I really didn't cope. I really did not find motherhood a pleasure. With the benefit of hindsight, I think I had some form of post-natal depression; it was totally different when I had our daughter five years later. I would say that for more than six months I really didn't enjoy being a new mum. I know I'm not unique in that, but I do wonder if it was all the stress that was going on at the time it was still there and affecting me. I was carrying quite a burden of worries.
- 78. There were other things, too. When our son was a babe in arms, we had a lovely holiday in Yorkshire. Malcolm was feeling better, but I accidentally closed his arm in the back door of the car. He had a huge bleed, but he didn't want to go to Oxford and have any more of their nasty blood products. It became too painful to bear and he thought he had to, it wouldn't go away. I had this enormous guilt that he would have Factor VIII and this time he would get HIV and it would be my fault. Every time he got more Factor VIII, they had to keep testing him because there were no guarantees.

Section 6. Treatment/Care/Support

- 79. About five years ago, Malcolm was due to have an operation for bowel cancer but at the last minute it was cancelled because they had to order fresh medical instruments due to his hepatitis C or any other blood bourne infection he may have acquired. His haematologist had prompted about the need for this. He was referred urgently by our GP with suspected cancer in August.
- 80. Everything progressed quite quickly. His date for surgery was postponed as the instruments had not been ordered and we were told they were not going to be available in the near future. Malcolm was stressed. I phoned and was told he would probably have to wait until next August for the instruments to arrive and the surgeon to arrange another slot.
- 81.I told our daughter, who works in head and neck cancer in a London Hospital. She asked for advice from her cancer consultant, who helped her write a letter about the possible implications. We do not know where they acquired the instruments from...we had even offered to use our savings to buy them as we knew from the press that they had financial problems. Malcolm was offered surgery by a different surgeon at an earlier date. He gratefully accepted. He had already waited 8 months. So the Hepatitis C infection still causes problems three decades later.

Section 7. Malcolm's medical records

82. When Malcolm first got hepatitis, we had recently been to Tunisia on holiday. The doctors said the hepatitis was probably something he got on holiday, even though we ate the same things. It wasn't a boozy holiday, as Malcolm didn't drink and they didn't even serve alcohol

because it was a Muslim country, but that's what the doctors blamed it on.

- 83. When I saw what Dr Trowell had written about Malcolm's alcohol consumption, I was fuming. I am the drinker in the family, not Malcolm. He has never been a big drinker. He dealt with so many road traffic cases involving alcohol that it put him off drinking. When he was younger, he only ever drank a few beers if he drank at all. By way of example, when Malcolm turned 30, one of his best friends bought him two big bottles of champagne. Those bottles sat there until our son got engaged and even then, at that celebration, Malcolm only had a tiny amount.
- 84. Recently I read an article in the newspaper; a man was dying from hepatitis C and he had developed liver cancer from it. He had been told he was drinking too much and that's what had caused it, but it turns out that he had hepatitis C.
- 85. As for comments about Malcolm's diet, I knew what he should be eating as I had worked with hepatitis patients before.
- 86. These comments made us very, very angry. Malcolm feels that Dr Trowell was trying to blame him for having hepatitis.
- 87. We also want to know where all the missing notes are. We have requested Malcolm's medical records, but the Churchill Hospital produced hardly anything.

Statement of Truth

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

Signed GRO-C

Dated <u>25 August 2019</u>

GRO-C

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