Witness Name: Malcolm MacRae
Statement No.: WITN3534001
Exhibits: **nil**
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF MALCOLM MACRAE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 07 October 2019.

I, Malcolm MacRae, will say as follows: -

Section 1. Introduction

1. My name is Malcolm MacRae. My date of birth is GRO-C 1965 and my address is known to the Inquiry.

2. I have two younger siblings: one brother and one sister. I have been married for 12 years.

3. I have severe haemophilia A and have used a variety of blood products throughout my life, including fresh plasma, cryoprecipitate and Factor VIII.

4. I intend to speak about my infection with Hepatitis C through blood products. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on my life.

Section 2. How Infected

5. I was born in 1965 and I lived just outside of Inverness with my mother, father and two younger siblings. My mother was the Head teacher at a small country school and my father was a civil engineer.

6. As a baby, I always had a lot of bruises and my mother was concerned that people would think I was subject to mistreatment. Initially, when she asked the GP about the bruises, he said that they were normal childhood bruises. However when this GP went away on holiday, a locum GP told my parents that these bruises were not normal. I was tested and subsequently diagnosed with severe haemophilia A. I was at that stage about 18 months old.

7. There was no history of haemophilia in our family and my younger brother was perfectly healthy. Haemophilia is a genetic error in the female half of my DNA, however this mutation does not seem to be in any of the women on my mother's side of the family, so it is clear that I was the first person to have this genetic mutation in our family.

8. Shortly after being diagnosed with haemophilia A, my parents moved into Inverness, where I was put under the superintendence of Raigmore Hospital. I think that I was one of two haemophiliacs being treated at Raigmore at this time. The other was called GRO-A, but he was sent away to a residential school in Fort Augustus, at the other end of Loch Ness. I know there was also a chap with haemophilia B being treated at Raigmore Hospital called GRO-A. GRO-A was treated there at around the same time as I was, but he used Factor IX.

9. When I was in school I was under the care of Dr Cook, the haematologist at the Raigmore Hospital. Dr Cook took a very personal interest in my condition and looked after me very well. He explained that I had severe haemophilia A, which meant that I had little or no natural factor VIII in my blood, and I had a natural level of Factor VIII in my blood of less than one per cent of a normal person, so I was seen at the hospital fairly regularly.

10. Dr Cook took a particular interest in me because there were not many haemophiliacs in the area. He was very caring and would come to visit my family and I to see how we all were doing. Although I could be cynical and say that our house was not too much of a detour on his route home, I think it was more than convenience and that he genuinely cared. He even took me to a Haemophilia conference in Dundee, to show everyone that if you care properly for a haemophiliac they can live a normal life. I remember being horrified when a few of the other haemophiliacs said that they sometimes wouldn't take the injection, even if they needed it. I realised how well Dr Cook had educated me on how to care for myself and how to manage my condition, as he had always told me not to wait – if I thought there was something wrong then I should take the injection as soon as I could. As a result of Dr Cook's advice, I was quite cautious. I think I only ever fell off of my bike once, and if I knocked myself or something happened, I knew that I should treat myself as soon as possible. So I was very well cared for. I remember that when I was 8 or 9 I would never catch childhood illnesses, and would joke that it was because I was always being inoculated against these things through my treatments. At the time this was much to my annoyance because it meant that I could never get out of going to school!

11. Initially I was treated with just raw plasma. I then started to use cryoprecipitate in around the late 1960s or early 1970s. I remember that this came in bags, and I do not think that as many donations were pooled to make it as is used for subsequent treatments. I had the cryoprecipitate every one or two weeks, as and when I needed it. My parents would

phone the hospital and it would take roughly two hours to thaw it out and it would be administered at hospital. From about 1973 onwards, when I was 8 years old, I started to administer cryoprecipitate myself in the hospital under the supervision of a doctor.

12. Within two years, by the time I was 10 years old, home treatment of Factor VIII was available so I could administer it at home by myself. It was administered on a needs basis as opposed to prophylactically, because there was insufficient supply for prophylactic treatment. Dr Cook always advised that I should only have Factor VIII that was made by the Scottish Blood Transfusion Service, based just outside of Edinburgh, because he knew that other products could be less reliable. He was quite clear that I should stick to Factor VIII made in Scotland. When I first started using Factor VIII, the infusions were 60 ml, which was a very large volume but only contained about 1000 units. Nowadays, the infusions are only 5 ml but the potency is significantly better; the 5 ml contains around 3000 units.

13. I remember having a very strong understanding of my condition and the risks associated with it from a young age. I seemed to know very early on what medication I was given and what the risks were. For example, I knew the correct procedure for giving myself injections and how important it was for this to be done properly. Dr Cook also explained to my parents and me that viral infection was a possibility from using the products. I do not remember whether Dr Cook was specific about where these viruses came from, but he said that some people had these viruses and could pass them on. I knew that blood from different donors was collected and pooled together to make Factor VIII. I also knew about Hepatitis A, B and Non-A Non-B from as early as age 7. My father lived on a croft and had known people who had contracted "jaundice", or as it is now known, Hepatitis A, so we were all aware of what Hepatitis was and definitely knew about the risks. Whist at secondary school, I remember a friend at school telling me about a Channel 4 programme he had seen about a new disease in the USA, AIDS, and how it was

passed on via blood-to-blood contact. I remember walking around the playground listening to him and thinking that this illness could come through the Factor VIII. However for me, the risk of not taking the treatment far outweighed the risk of taking it. I still believe this is true and I know that I would not be here today if I had not continued to take the Factor VIII.

14. Occasionally I would get an allergic reaction to the Factor VIII injections. This was unusual and the allergic reactions were usually very minor; I would feel slightly hot and funny. Normally I would just take an antihistamine and this would be sufficient to quell the allergic reaction really quickly. I think Dr Cook may have explained that these allergic reactions might mean there was something in the injection, but he did not specify what that was.

15. At some point in about 1978, when I was around 13 years old, I had a particularly bad reaction to the Factor VIII injection and I believe that this is when I was infected with Hepatitis C. The allergic reaction was so bad that I had to be hospitalised for a few days; this was the first and only allergic reaction that necessitated hospitalisation. I did not express any particular concerns to Dr Cook about the gravity of the allergic reaction and I am not sure what, if anything, was said to my parents about the cause of it. I do not think that Dr Cook withheld anything from us on purpose. I cannot remember if it was explained to me that it could have been related to Non-A Non-B Hepatitis, however I believe Hepatitis C was not detectable until about 1982, so even if I had been tested for the virus after the allergic reaction, the medics would not have been able to pick it up. When I was released from the hospital I continued to take Factor VIII.

16. At the time of the allergic reaction Dr Cook was nearing the end of his career, and he retired a little while after. Once Dr Cook retired Dr Tom Taylor took over my care. Dr Taylor was caring but not as personally involved as Dr Cook had been, however this is not a criticism, just an

observation. I believe that Dr Cook had been personally interested to an unusual degree, possibly because he saw me as a success story.

17. In 1984 or there about, I had been under the care of a dentist at Raigmore Hospital due to my haemophilia. I remember that on one occasion, I went to my appointment and it was not my usual dentist. Usually, people only go to the hospital dentist when their teeth are really bad. As my teeth were fine, this dentist was rummaging through my files to try and figure out why I was there instead of simply asking me. Eventually he said 'oh, I see that your Hepatitis B has cleared up!' He must have found a reference to Hepatitis somewhere in my file, but this was the first I had heard of it. I do not know if the file specifically said Hepatitis B, or whether it had just made reference to Hepatitis more generally and the dentist assumed it meant Hepatitis B because this was one most people knew about at the time. I was slightly taken aback by what he'd said but knew that I was in the chair because I was a haemophiliac. In actual fact I wasn't unduly surprised by the fact I'd been told I had Hepatitis B as I had previously been warned of the risk of virus infection. However this was prior to my Hepatitis C diagnosis.

18. I was not officially diagnosed with Hepatitis C until the mid-1980s when I was living and attending university in Edinburgh. I had remained under the care of Raigmore Hospital during my first year of university (in 1983), but by 1984/5 I was under the care of the Royal Infirmary of Edinburgh. Initially I attended a general clinic at the Royal Infirmary that catered for many conditions including haemophiliacs and diabetics; we were all just grouped together. The doctors would ask how my 'condition' was, and I quickly realised that that they had not looked at my notes. I would just reply with 'the same as usual', and try to catch them out. However later, in about 1985 or 1986, the Royal Infirmary formed a specific department for haemophilia where a specialist saw me. These reviews were a lot more formal, and it was during one of these reviews, in approximately 1986, that Hepatitis C was mentioned. I do not remember getting much

specific information, however my memory of this period of time is somewhat foggy.

19. One of the things that I remember from when I was diagnosed with Hepatitis C was that I was assured that it was nowhere near as severe as Hepatitis B, so I did not need to worry about it. I believe that that was the generally held view at the time and that the consultant told me this as he believed it to be true. The virus had only recently been identified so the medical profession did not have much knowledge of its progression. I recall that while I was at university they had also found other strains of Hepatitis, D and E, and the assumption at the time was that none of them was as severe as Hepatitis B. I also remember that when I was diagnosed, they said that they were working on a treatment for Hepatitis C, but as far as I am aware there was no treatment or cure for the virus at that time. I was aware that the risk of not treating myself was greater than the risk of treating myself.

20. Following diagnosis, I was brought in for a special review where they talked about the risks of Factor VIII and told me that it was now going to be heat-treated. I remember that I was not too happy about this because they explained that one of the downsides of heat treatment was that the material would lose some of its potency, and I had to use more Factor VIII as a consequence. I remember asking whether I could stay on the non-heat treated Factor VIII and being told that this would shortly become unavailable. I think that I had to sign a consent form to go from the non-heat treated to the heat treated Factor VIII. They also took blood from me at that time so that if something went wrong, they could compare my blood before with my blood after – they did this every time my treatment changed. I think everything was quite well explained and that when they told me about the infection they gave me all of the knowledge and information they had available to them at the time.

21. When I was diagnosed with Hepatitis C, they did tell me not to share toothbrushes or razors and that I needed to take certain additional

precautions. I think most of what they said was common sense. I had been sticking needles into myself since I was a child so I was already well aware of the risk of blood spills, it was already part of the routine of being a haemophiliac.

Section 3. Other Infections

22. I do not believe that I have contracted any other infections from my use of blood products, although I cannot be definitive about this because of the dentist's comment about Hepatitis B back in 1984. However, as I have already explained, I have always put his comment down to ignorance because my medical records may have just referred to Hepatitis and he made an assumption that it was Hepatitis B.

Section 4. Consent

23. I do not believe that I have been treated or tested without my knowledge or consent. Every time my treatment or the supplier of the treatment changed I had consented to it. Often treatment was couched in terms of 'if you consent you can have the new treatment, but if you do not then you will not be able to have the old treatment for long as it will shortly be unavailable.'

24. I do not believe that I have been treated or tested for the purpose of research without my consent. In about 2014, I volunteered myself to trial a new treatment for Hepatitis C. Professor Hayes - the doctor who informed me about this treatment - never approached me asking if I would be a guinea pig; I offered to do this of my own volition. He did not solicit me to try it in any way at all. Having been treated from a very young age, and also having been aware of the treatment I was receiving and what was happening with my condition, I do not believe that I was ever experimented on in the slightest. I feel that my doctors have been very open with me, so if they ever wanted to try something on me they

would have just asked. I think that the level of care and attention I have received has been above average. In every profession there are rogue individuals who may be a bit unorthodox, but I do not believe that there was any conspiracy to experiment on me during my care.

Section 5. Impact

25. In 1993 I had an endoscopy to look inside my stomach, because varices in the stomach can be a sign of liver damage. They did not find any varices in my stomach. They also did a liver biopsy, but the issue with a biopsy is that the cirrhosis of the liver is not usually uniform – some points may be damaged and other parts may be fine, so it is rather a hit or miss procedure. I believe they managed to pull off an unaffected part of my liver when they did the biopsy, so when the results came back there was no evidence of liver damage.

26. In 1995 I was put on my first treatment for Hepatitis C, a six-month course of Interferon. They warned me that I might feel tired while taking the treatment. At the time, I was working halftime at Napier University as a lecturer and I remember a colleague saying that I looked as though I was working too hard. I think that this was because I was tired and rundown from the treatment. I was very tired throughout the treatment, but felt I could manage as I was only working half time. I also think that my behaviour changed while I was on the treatment; a bit less tolerant and more argumentative. When I finished the course they did tests and the result showed that although it had reduced the level of Hepatitis C in my blood, I had not cleared the infection.

27. At the backend of 2000 I had my second course of treatment for Hepatitis C. This time I had Interferon and Ribavirin – the Ribavirin was meant to enhance the effect of the Interferon. As far as I can recall, I think that I was meant to be on this treatment for a year but I could only endure it for 6 months. This treatment was a lot more difficult to deal with than the

first one, and by the end of the year I was so unwell that I had to take two weeks off of work over the Christmas period because I was unable to concentrate properly. I also experienced some other slightly odd health problems while on the treatment, such as terribly dry skin and all sorts of other odd things going on. It was during this treatment that I started to have slightly disturbing thoughts, not suicidal but rather a kind of temptation in the back of mind to harm myself, in order to get attention. I had never had these types of thoughts before the treatment, nor have I had them since. They disappeared as soon as I stopped taking the treatment. I stopped taking this treatment in around March 2001, because the tests showed that my viral load had not dropped enough to warrant me continuing the treatment for the full year. I was also told that my Hepatitis C genotype was 1a, which is particularly difficult to treat. The doctors told me that the Interferon and Ribavirin were costly treatments. They said that, because my response to the treatment was so poor, it was unlikely to be successful and it might be better to redirect resources to someone who would be more responsive to the treatment. I agreed with this and felt like the treatment and associated resources should be targeted to someone who would have a better chance than me. I felt that had I disagreed or protested they would have kept me on it. There was nothing at the time to suggest that I was being treated because I had contracted Hepatitis C through contaminated blood products; it appeared I was being treated because I was unwell and needed it.

28. The next round of treatment I underwent was in 2005. This time I was using three drugs: Interferon, Ribavirin and another drug that I cannot recall the name of. This treatment was terrible. I had absolutely no energy, permanent flu like symptoms and I constantly had to take paracetamol to counteract the flu-like symptoms I was experiencing. I was sleeping a lot but was still very irritable from the tiredness, and as a result fell out with quite a few people. At this time I was still doing my teacher training at Moray House, so I had to spend time in bed whenever I was not teaching. I was on this treatment for about 4 or 5 months, but

stopped taking it because it was not making a significant difference, and I could again see the need to give this expensive treatment to someone else with a genotype easier to treat who would really benefit from it.

29. Professor Hayes, a consultant hepatologist at the Royal Infirmary of Edinburgh, had a specific interest in Hepatitis C. He attended some of my medical reviews at the haemophilia centre in the Royal Infirmary Edinburgh and would often be on hand to answer any of my questions. He also gave me updates on new treatments. In 2013, Professor Hayes mentioned that there were clinical trials going on for a new drug that would be suitable to treat my genotype, and that they were yielding positive results. He later told me that they had passed the clinical trials and they now just needed to get the funding through the Scottish Parliament to begin wide scale trials. I told him that if he needed any guinea pigs to try the new treatment, I was happy to put myself forward. At the end of 2014, I started my final treatment for Hepatitis using this new treatment, which came in the form of tablets. While it had not been explicitly stated, I believe that I was the first person in Edinburgh, or even the whole of Scotland, to take this treatment. This treatment was a lot easier to deal with and I had a much better experience on it than on the previous treatments. I do not remember having any major side effects or it being particularly unpleasant. I completed the treatment after 6 months, around mid-2015. Once I finished the treatment, they tested my blood 6 weeks later and I was told the virus was undetectable. I was then tested after another 6-month interval and it was confirmed that I was clear of hepatitis C.

30. Since getting rid of the virus I have noticed that my memory has improved greatly on a day-to-day basis. However there are still large gaps in my memory that I do not remember; slowly things are coming back but not everything. Since clearing the virus I also realised that while I had Hepatitis C, I always seemed to wake up with mild hangover symptom's. This was not something I noticed at the time prior to clearing

the Hepatitis C as I had felt like that for over 30 years, but since clearing the virus I definitely feel better first thing in the morning.

31. Aside from the poor memory and difficulty concentrating, another thing I noticed was that while I had Hepatitis C my veins were very deflated and difficult to find. I think that this was from being run down. Since clearing the virus, I feel like my veins seem more bouncy. I also noticed that prior to the treatment I suffered quite a lot from water retention; my ankles and lower legs would swell up. My wife has also told me that I sometimes had halitosis before clearing the virus and would sometimes have a definite green hue to the whites of my eyes and my skin had a slight yellowish tinge. At the time I attributed all of these things getting old. I just thought that things were falling apart more quickly for me than for other people because I was a haemophiliac. On reflection, I think the Hepatitis C caused an accumulation of small symptoms that I had not been able to attribute to the virus. I did not know how much the Hepatitis C had affected me until I cleared it.

32. I still get tested for liver function every six months as part of my haemophilia review. I also have an ultra sound every six months to monitor the health of my liver but I do not usually ask about the results. I have always taken the view that I only want to know if there is a change, and have made this clear to my specialists. I do not know the extent of the damage to my liver, but I know that it has definitely been affected by the Hepatitis C because when the Skipton Fund came along there were certain criteria you had to satisfy in order to claim certain benefits. One of these tests was a sonic ultrasound to screen my liver. I know that I failed this test and was entitled to certain benefits from the Skipton Fund as a result, suggesting there has been damage to my liver.

33. Although I appeared to recover quite quickly from the allergic reaction I experienced in 1978, I believe that there were subsequent changes in me and I just wasn't the same as before the allergic reaction. At the time I was in my first or second year of secondary school at Inverness Royal

Academy. I had always excelled academically throughout primary school and been regarded as top of my class; I had been bright and intelligent, with a very good memory and able to pick things up easily. However, subsequent to the allergic reaction and hospitalisation my concentration and academic ability started to slip. My energy levels were depleted and I felt like I needed a lot more sleep. I remember at the time of the reaction I was reading the second volume of Lord of the Rings, and although I had previously read voraciously, I just could not get through it. I would definitely say that my marks were less favourable following the allergic reason and suspected infection with Hepatitis C, and although I did well in maths and science, I did not do so well in other subjects like languages. At the time, I put all of this down to becoming a teenager, my hormones kicking in, and not putting enough effort in at school. However now I look back and wonder if I physically couldn't put more effort in due to the Hepatitis C, because as time progressed it became clear that there were definitely issues with my memory.

34. I had always wanted to be a haematologist but you needed at least 5 A's at Higher Grade to be able to get into university to study medicine. By the time I was 14, I knew that I did not have the memory needed to achieve these types of grades. I then decided that I wanted to become a lawyer, but a few years later it was pointed out to me that my reading was not quite as voracious as it should be and that law was a very competitive profession. Someone suggested that I follow a career in maths, as this is where my strengths lay. Therefore, when I was 18 years old, I left school and went straight to Edinburgh to study at Heriot-Watt University. I studied Actuarial maths and statistics for four years. I graduated with a third class honours, and I certainly think that my memory and difficulty concentrating got in the way of things.

35. When I left university I started working at a life insurance company as a trainee actuary, however the company went up for sale at the end of 1990. In early 1991 I decided that, because I had only got a third class honours, I should go back to university to repair the error. At this point I

still thought that I had got those grades because of my own laziness. I went back to Heriot-Watt and did a Master's degree in mathematics. I threw myself heavily into studying. One of the lecturers later told me that because of my undergraduate grade they were not really expecting me to do well, and that my performance well surpassed their expectations. However I really exhausted myself while I was doing this because I was studying so hard. I worked one night a week as a barman in a quiet hotel in Edinburgh, but other than that I just focused on studying. I finished my masters in September 1992.

36. After I got my masters I went on to do a postgraduate diploma in computing at Napier University from September 1992 to June 1993. I decided to do this because my masters had focused on the mathematics of non-linear models, and I knew that the actuarial profession was going down a route that would require a certain level of computing skills. I wanted to be able to go to an employer and say that I not only had some actuarial exams and a masters in mathematic modelling, but that I also had knowledge of computing. I found the postgraduate computing course much easier than my masters and it really suited me.

37. When I finished my postgraduate course in 1993, I was looking for jobs and managed to get one as a university lecturer at Napier University in maths and statistics. This was a temporary job because it was initially a maternity cover, but instead of taking on one lecturer full-time for the year they took on two half-time lecturers. A half-time job suited me, because at this point I was still really tired. As I was teaching maths and statistics to business students and lawyers, the mathematical level of the teaching did not challenge me much intellectually. This meant that I had the time and energy to develop my own teaching material and skills and pursue other interests without over stretching myself or getting too tired.

38. In 1996, during the time I was working part-time at Napier, a friend of mine who was a Senior Actuary at Standard Life asked me to come and work for him on a part-time basis. I continued to work at Standard Life

and Napier until April 1998. Although the lecturing role at Napier had only been a one year contract, at the end of each contract it would get extended and just continued to drift on in different guises. I was told that I would never get a full time job there unless I got a PhD or qualified as an actuary. Therefore, at the end of 1997, I registered for a PhD at Napier University. However it was only a few months later in April 1998 that I was diagnosed with cancer and my studies really collapsed and ceased altogether.

39. In April 1998, I was diagnosed with testicular cancer from an undescended testicle. By the time they found it, it was the size of an orange and there were multiple lesions on my lungs to where the cancer had spread. Usually, most boys who have an undescended testicle have a small operation at the age of around 10. The GP who had treated me in Inverness when I was younger had been unwilling for me to have this operation, probably because he thought that unnecessary surgery on a haemophiliac ought to be avoided. While this was probably the right choice at the time, I later found out that if left alone an undescended testicle is 40 times more likely to become cancerous. My understanding of the current situation is that because haemophiliacs have less clotting factor, post-operative care might be easier in some respects, as in haemophiliacs it can be easier to control clotting after surgery and avoid blood clots. However, I do understand why the doctor made that decision, because when I was 10 years old there was limited amounts of Factor VIII, so the immediate risks associated with me having the surgery may have been greater than it would be now.

40. I saw an oncologist named Dr Howard at the Western General Hospital in Edinburgh. Dr Howard said that I was his first patient with haemophilia and was aware that I had Hepatitis C, but he did not think that the virus would affect the treatment. I went through 18 weeks of treatment and the cancer cleared up. After they had killed off all of the cancer cells I had surgery to remove what they termed 'The Dead Mass'. During this time, I had to give up work in order to recover from the treatment as I

understood that as my work positions at that time were temporary part-time, so they did not come with sickness benefits.

41. After I had cleared the cancer I went back to work and decided that instead of the flexible part-time work I had been doing, I wanted to go back to doing actuarial work. I started back at work in February 1999 with an actuarial consultancy firm in Glasgow as an actuarial analyst, and this was a lot more tiring than the work I had been doing previously, as I had to travel from Edinburgh to Glasgow each day. It was while I was working here that I started the combined Interferon and Ribavirin treatment, and I had to take two weeks off of work over Christmas 2000 due to feeling so unwell from it. This was very significant for me because I had always tried to avoid having days off of work in the past, in order to avoid having awkward questions from employers about my haemophilia. I went back to work in January 2001 and at this time the company I was working went up for sale. By this point, I was very tired from the combined treatment compounded with my commute to and from work, so in March 2001 I decided to get a job in Edinburgh.

42. In 2003 I was working as a senior actuarial analyst at HSBC Actuaries and Consultants Limited in Edinburgh and also studying for my actuarial exams. The work was very intense and I was experiencing extreme Hepatitis C related tiredness. Eventually I had enough and handed in my notice in March 2003. At the time I thought that I was not enjoying the actuarial work, however in hindsight I think that I was just unwell and tired. Anyway, at the time I decided to stop this type of work and try to become a maths teacher as I had previously enjoyed teaching at Napier University so much. I started my teacher training at Moray House College of Education, part of Edinburgh University, where as part of my course I taught maths to secondary school students.

43. When I was undergoing the third round of treatment in 2005, I was still doing my teacher training at Moray House College. Although the assignments were not difficult, I found that I had great difficulty in

completing them. My energy levels were getting progressively worse over time due to the Hepatitis C and the treatment. I even remember falling asleep at one point during a lecture. It had become clear to me that I was struggling at Moray House, so although I was offered a probationary teacher placement at Millburn Academy in Inverness, I never managed to take up the placement or complete my teacher training.

44. After Moray House I drifted for a bit before being offered a placement with Hazel Carr - a specialist resourcing and outsourcing company - in August 2006. They found me a temporary role as a senior actuarial analyst in St Albans. In October 2006 I set up my own company with me providing a temporary actuarial resource. For the past twelve years I have been doing temporary actuarial work, which suits me more because it allows me to work when I want and suits my needs. I never passed the final actuarial exam to become fully qualified because it is a 7-hour exam. Although I feel that I know all of the information and can do the work, I simply did not have the stamina, energy or concentration to sit an exam for this long. I have tried to sit it 7 times and have failed on each occasion. I have come to the decision that I do not need to take this exam because I have been relatively successful without it. I know that if it had not been for the Hepatitis C and undergoing all of the treatments I would have passed it.

45. If I did not have Hepatitis C I think that I would have excelled professionally and academically. I would have passed those actuarial exams if the virus and the treatment had not affected my memory. I also think that I would have stuck with my career and stayed in the same job. I am definitely not better off than if I had not been infected with Hepatitis C. For example, if it were not for the exhaustion caused by the infection and treatment, I would never have gone down the contracting route and probably would have a permanent job in which I could have progressed more. I would have chosen to study medicine if I did not have Hepatitis C, as my concentration and memory would not have been affected so

much. I would have been achieved the necessary qualifications I needed to study medicine at university. Similarly, I could not pursue a career in law because the impact the virus had on my concentration, which meant that I could not read things fast enough or skim read as effectively as the discipline requires. So my first two career options never took off due to the virus.

46. My parents were extremely worried when I was diagnosed with Hepatitis C. My mother blames herself because she thinks that if I did not have haemophilia I would not have contracted Hepatitis C. Quite recently my mum said something that implied that she still blamed herself for me getting the virus. I had to explain to her that it was not her fault because I am the defect, so she did not pass the haemophilia to me. Even if she had passed haemophilia on to me, the blood products were the only treatments available for haemophilia at the time and they could not detect Hepatitis C until much later. I know very well that without the Factor VIII, I would not be here today. When I was 14 or 15 I had a really bad bleed into the kidney and would have died if it were not for the Factor VIII. I have faced my own mortality and know full well that if Factor VIII had not been given to me when it was, I would have been dead well before now. So while I may not have caught Hepatitis C had I not used the Factor VIII, I would also not have been able to enjoy some level of life.

47. I have always tried to ensure that the tiredness does not affect my social life, as this is something I really enjoy.

48. I definitely believe there was stigma growing up in relation to being a haemophiliac. After the Chanel 4 programme about the beginning of AIDS (the one my school friend told me about) there was a strong public perception that all haemophiliacs had HIV, and so I hid the fact that I had haemophilia for a number of years. For example, my ankles have been slowly degenerating for a long time and have caused me to have a limp. However if anyone ever asked about my limp, I would make something

else up just to avoid telling people that I had haemophilia, in case they assumed that I had HIV. Until quite recently I have never been open about my haemophilia, because in people's mind they think that if you have haemophilia you are an AIDS risk. Even now I feel that the way the press talks about these things can give the impression that haemophiliacs are at a continued risk of HIV. Obviously the Inquiry is a good thing, but the press can always have a flip side and can promulgate the stereotypes about haemophiliacs and HIV.

49. Although I was secretive about my haemophilia with the outside world, with my family members I never really hid my haemophilia, nor do I believe there was a stigma attached by family members. When I was younger if I was staying with a relative I had to pack the Factor VIII up in an ice pack and store it in the fridge, so you could not really hide it.

50. In terms of HCV, I do not think there was such a stigma about it because in the 1980s the press did not talk about it nearly as much as they did about HIV, so HIV overshadowed it to a large extent. However nowadays I think that there is an assumption that if you have Hepatitis C you are a drug abuser. I think that the Scottish Government do not help to dispel this association because they often conflate drug users with Hepatitis C while discussing policies.

51. I do not think that my dental or medical treatment has been impacted on negatively by having Hepatitis C. I have found that if I need something done, it happens quickly, and I feel that I have always received good medical treatment.

52. One of the things that I have noticed over the years is that there seems to be a lot of ignorance in the medical community. For example, when I was first diagnosed with cancer in April 1998 it was customary to offer males the opportunity to give a sperm donation. I was sent to a sperm clinic in London because I had Hepatitis C. The specialist at the clinic told me that there was a one in three chance that I would pass Hepatitis

C to my child via my sperm. I know that it can be passed from mother to baby through blood-to-blood contact due to complications at birth, but I had never heard about the risk of passing it on through sperm.

53. On another occasion in 2004, the father of a friend of mine, who was a senior pathologist at Raigmore Hospital, told my friend that Hepatitis C was a sexually transmittable disease. When I told my friend that this was not true, she told her father, who went to speak to a haematologist at Raigmore to confirm what I had said. It just goes to show that even as late as 2004 there were senior pathologists who were ill-informed about Hepatitis C.

54. While, I think that the level of ignorance in these situations is regretable and there has definitely been a certain level of ignorance in the past that caused mistakes, I do not think that I personally have experienced any purposeful or deliberate mistreatment. I think that it was just ignorance. I have never felt that there was a conspiracy. I believe that the medical staff were always honest with me based on their state of knowledge at the time. I do not believe that there was any unnecessary withholding of information or delay in offering me treatment - hindsight is a great thing, but ignorance is something that can be pervasive.

Section 6. Treatment/Care/Support

55. I have not faced any difficulties or obstacles in obtaining treatment. In fact, as I have already stated, I feel that I have received incredible care and been seen quickly throughout my life. I do not believe that the level of care I have received could have been surpassed anywhere else – it may be matched but I do not see how it could be better elsewhere.

Section 7. Financial Assistance

56. In 2003 I received my first initial lump sum from the Skipton Fund. In late 2010, I think the amount I received was increased to £50,000. Currently I receive £27,000 per annum from the Scottish Infected Blood Support Scheme (SIBSS).

57. I appreciate the money I have received from the Skipton Fund and now the SIBSS, because as can be seen my career has changed quite frequently so my pension provision is not a sensible as it would otherwise have been. Therefore, receiving financial assistance for life is a huge help in filling this gap. However I think that the Scottish Government was quite crafty because when it introduced SIBSS, they said that it was more money than people in England receive, however the legislation makes no provision to increase the amount individuals receive. So whereas state pension goes up with the RPI or CPI, the financial assistance provided by the SIBSS does not. Apparently there have been indications on social media that there may be an increase to individual payments from next April, but I believe that this would have to be at the discretion of the Scottish Government, as there is no provision for this increase in the legislation. This lack of certainty in an increase is a cause of worry for me.

Section 8. Other Issues

58. I was never part of either the Penrose or Archer Inquiries because at the time I did not realise how much having Hepatitis C was affecting me. I wanted to get involved with this Inquiry because I missed the others.

59. I believe that most of the problems of infected blood have been caused by ignorance as opposed a conspiracy. I do not believe that there is any one person to blame for what happened. I think that this Inquiry would help massively if it could allay fears that there was some big conspiracy or cover-up. I hope that this Inquiry will highlight some of the deficiencies in the system. Similarly, I believe that the press can often get things wrong and cause misconceptions about haemophiliacs, and I think that

it would be helpful if the Inquiry could help to lay some of those misconceptions to bed.

60. I also hope that the Inquiry will review the fact that people in different areas of the UK are entitled to different levels of financial support, as it seems arbitrary and unfair. If I were to move to Wales or England, I could end up getting significantly different financial support than if I were to remain in Scotland.

Statement of Truth

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

Signed GRO-C

Dated 7/1/2020

Use of my statement

I, Malcolm Macrae, confirm that by submitting my signed written statement to the Infected Blood Inquiry, I understand it may be used in the following ways:

- publication on the Inquiry website;
- reference and/or inclusion in any interim and/or final report;
- disclosure to core participants and where instructed, their legal representatives via the Inquiry's database or by any other means as directed by the Chair of the Inquiry;
- disclosure to any person or organisation, including any instructed legal representatives, who is the subject of criticism in my written statement, as set out in the Inquiry's Statement of Approach - Anonymity and Redaction.

I also confirm that I have been advised of the option to seek anonymity and that if granted my identity may nevertheless be disclosed to a person or organisation, including any instructed legal representatives, who is the subject of criticism in my written statement in order that they are afforded a fair opportunity to respond to the criticism.

☐ *Please tick this box if you are seeking anonymity, in which case consent is considered to be provided subject to the determination of any application for anonymity.*

Signed M. C. MacRae

Date 7/1/2020

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