Witness Name: Andrew Martin Statement No.: WITN3785001 Exhibits: None Dated: 2021

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ANDREW MARTIN

I, Andrew Martin, will say as follows:

Section 1: Introduction

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 My name is Andrew Martin. My date of birth is <u>GRO-C</u> 1951 and my address is <u>GRO-C</u>. I live with my wife and I have a step-son and six grandchildren.

Section 2: How infected

Haemophilia

- 2. I have Haemophilia A. When I was diagnosed with the condition at around 18 months old, it was categorised as mild and due to this, my treatment is 'on demand' for example if I experience trauma or if I require an invasive medical procedure.
- 3. I was diagnosed after my late brother, who was four years older than me, had a bleed and was taken to hospital. The bleed appeared as a bad bruise and due to this, it was suspected that my parents were hitting him and they were

subsequently investigated by Social Services. Fortunately, one of the haematologists in the hospital was a haemophilia specialist and diagnosed my brother with haemophilia. I was immediately tested and it was confirmed that I also had haemophilia.

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- 4. As I was a mild haemophiliac, my life continued as normal. I went to a main stream school and did the normal school curriculum. Most of the injuries which I suffered were things like sprained ankles and at that stage, the only treatment was bed rest and an ice pack. I do recall having teeth out on two occasions in hospital, one when I was around 10 years old and then 17 but as far as I know, I did not receive any blood products, I was just monitored.
- 5. I have been treated at a number of hospitals during my lifetime, the details of which I set out below. I cannot recall ever being informed about the risk of contracting Hepatitis C via blood products by any of the hospitals that were treating me at the relevant time. I did become aware of the risk of HIV which I will discuss in further detail.
- 6. I did not in fact receive any blood products until I was 19 years of age. I was at Hull University at the time and had caught my leg on a table. I eventually attended Hull Royal Infirmary where I was given Cryoprecipitate. I did not receive any other treatment until I was 31 years old.
- 7. I was married to my first wife at this time and due to both of us pursuing our careers, we decided not to have children. My first wife was a deputy head mistress of an infant school and I was applying for deputy headships of secondary schools. After a long conversation we decided that I would have a vasectomy. Initially I attended my own GP in Devon where we were living. I was referred to a consultant in Exeter and we had a conversation about my haemophilia, that it was mild and I had no real issues with it during my lifetime and he confirmed that the procedure could go ahead.
- In Spring 1982, my first wife was appointed as a head teacher in Hampshire and I had been contacted by Hampshire Education Authority and asked if I

would be interested in a job as head of the mathematics department starting at the same time as my first wife. Because of the timing, we wanted to have the procedure done quickly so we decided to go private at the Nuffield Hospital in Exeter. I informed the hospital about my haemophilia but the consultant did not contact the haemophilia centre prior to undertaking the procedure, he confirmed that it would not be an issue and the vasectomy went ahead in June 1982 on a Friday. There were no bleeding issues during the procedure and everything seemed to be okay.

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- 9. During the weekend, I started to bleed internally and by the Monday, I was in a lot of pain and very swollen. I contacted my GP who came out to see me and it is the first and probably only time I have heard a GP swear. He was so shocked about the bleeding and swelling that he sent me straight to the Royal Devon and Exeter Hospital where I was admitted.
- 10. I recall that when the haemophilia consultant came to see me in the hospital, he was quite angry that I had undergone the procedure and no one had arranged any cover with blood product in the event of a bleeding episode. At this time, due to my infrequent treatment, I was not even registered at a haemophilia centre. Due to the passage of time, I cannot recall the name of the haemophilia consultant that saw me.
- 11. I received my first dose of Factor VIII at this time. I was in hospital for around two weeks and I had regular Factor VIII infusions. In total I received circa 80,000 units. This was the first time that I had heard of Factor VIII and I recall asking the consultant about it because I had heard little snippets in the news that some haemophiliacs were contracting AIDS in America. I asked him if the product they were giving to me was safe and he replied that it was perfectly safe as I was receiving the British product.
- 12. When I was discharged from hospital, I was still unable to work and had to take sick leave for the remainder of the school term.
- I moved to Hampshire in August 1982 and my haemophilia care was transferred to Southampton General Hospital. After the trauma of the vasectomy, I had

regular consultations with the haemophilia centre and started the 'on demand' regime for treatment that has continued ever since. During this period of my life, I did have a number of sprained ankles that were treated with Cryoprecipitate.

Diagnosis with Hepatitis C

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- 14. In 1986, my haemophilia care transferred to Hammersmith Hospital when I moved there after I secured a job in the Education Department in Hounslow. This is where I met my second wife who was also working there.
- 15. When I was in the care of Hammersmith Hospital, I had to have two wisdom teeth removed. I believe that I received whole blood in respect of those procedures but I cannot be entirely sure. I also attended Hammersmith Hospital for regular appointments and I had a feeling that they were monitoring me. On one occasion they commented that my liver function test was abnormal but they were not sure why this was happening. Eventually, they started to refer to it as Non-A Non-B Hepatitis (now known as Hepatitis C) but I was not, as far as I can recall, formally diagnosed at this point. I was told it was nothing to worry about but I was not given any information about it during the entire time I was registered at Hammersmith.
- 16. In 1989, my haemophilia care transferred to the Royal Hallamshire Hospital haemophilia centre and I am still registered there. I have had a very long and pleasant relationship with the Royal Hallamshire Hospital. My clinician was originally Professor Eric Preston and then Professor Michael Makris but he is now moving on and it is currently Dr Rhona Maclean.
- 17. I must have been formally diagnosed with Hepatitis C at some point prior to or during 1993 as this is when my medical records indicate that I received my first treatment with Interferon but I cannot recall specifically being told about my diagnosis. I think it was around this time that I became aware of the dire consequences of Hepatitis C because people were dying because of it but noone was providing any informative information. It was not until 1997 that the impact of Hepatitis C became apparent to me.

Section 3: Other infections

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18. I have not contracted any other infections. I did receive a warning letter from the Royal Hallamshire Hospital in 2005 informing me whilst I had not been identified as an individual who had been exposed to batches of Factor VIII contaminated with vCJD, I was 'at risk'.

Section 4: Consent

- 19. I believe that in July 1984 during a regular consultation with Dr Morag Chisholm (the head of Southampton Haemophilia Centre) I was offered a test to check my HIV status. At this time, the AIDS scare was very prominent. She was very clear that if the outcome was positive there was nothing which could be done with an almost certain death resulting. It was a very calm discussion and I felt I had to know whether I had been infected or not and so had my first test. I received the results of the test by post and was beyond relieved to be negative. I was due to be in school that day as term was approaching and I was ecstatic to share this news with my colleagues. However, a while later, the hospital said that they were not sure what the incubation period was so I would need to be tested again.
- 20. In relation to Hepatitis C, I was never told that I was being tested for it. As far as I was aware, I was having routine blood tests, my liver function was being monitored but I was happy with this.
- 21. My second wife who has been with me the whole time through the Hepatitis C diagnosis and treatment has never been offered a test for Hepatitis C although I am sure that the Royal Hallamshire Hospital would do one if I asked them to.

Section 5: Impact

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Impact of Hepatitis C

- 22. The infection with Hepatitis C itself did not have any impact on me until I had a hip replacement operation at the Royal Hallamshire Hospital in 1997. It was done in consultation with the haemophilia team and the orthopaedic team. Unfortunately, after the operation, they could not stop the bleeding and although I had received a significant amount of Factor VIII, it did not initially resolve the issue. Instead of being in hospital for a week or so, I ended up being in hospital for three weeks and I had a lot of discomfort, a lot of bleeding and a lot of bruising. Professor Preston, who was one of the leading hepatitis clinicians in the haemophilia field, had been monitoring my liver function and the view was taken that the damage caused to my liver by Hepatitis C was contributing to the Factor VIII not working effectively. Eventually the bleeding issues resolved but it was a very painful and uncomfortable experience. This was really the first time I became aware of the consequences of Hepatitis C for me.
- 23. I was due to have a liver biopsy in 1997 but due to the problems which I was experiencing, it was deferred until 2000 this is when I was told that I had cirrhosis of the liver. I recall the conversation with Professor Makris in his office when he informed me that my liver function was deteriorating and I became concerned at that point.
- 24. I had to have hip revision surgery in 2009/2010 and due to my experience in 1997, I was very apprehensive about it but it was not as bad and there were no issues with the Factor VIII working effectively. I have had a number of bleeds since but I have not experienced any issues with Factor VIII.

Treatment for Hepatitis C

25. I can ascertain from my medical records that the first treatment I was offered was in 1993 which was with Interferon. It was Professor Makris who put me forward for it. The course of treatment was six months of injections, three times a week and I cannot recall there being any significant side effects. However, the treatment did not work.

- 26. After I had had the liver biopsy in 2000, I was given the treatment of Interferon and Ribavirin. I started the treatment in May 2000 and finished it in May 2001. I recall being told that although my liver was damaged, the hospital wanted to see if the combination treatment would work.
- 27. I remember that in July 2000 I had a severe reaction to the treatment and suffered with severe eczema on my legs. It was so bad that I scratched it so vigorously that I bled significantly. I was referred to a dermatologist to see if they could help. I remember discussing whether I should stop the treatment with Professor Makris and he appeared concerned about it but ultimately the dermatologist resolved my eczema and I willingly carried on with the treatment.
- 28. From reviewing my medical records, I can see that I repeatedly complained about headaches and that I was tired the whole time I was on the treatment. I think that I put it down to the fact that I was busy at work, I was a senior education officer in the Local Authority Education Department in Doncaster by this time and I was involved in major school reorganisation programs which meant that I had a lot of evening meetings.
- 29. I know that I experienced a change in demeanour too whilst I was on the combination treatment, mainly at work. At home I was fine, my wife was very supportive but at work, I could be tetchy at times. On one occasion I flared up in a meeting, swore profusely and stomped out of the meeting. I was lucky to keep my job and on the way home, I was thinking 'I shouldn't have done that, this will cause problems tomorrow' but fortunately, went I went back into work, the person who I swore at came straight into my office and expressed that she was concerned about me. I had told my colleagues that I had haemophilia and they were very supportive. I did this because prior to starting my previous job in Hounslow, I had been advised not to disclose my haemophilia but it came out during the course of my employment and my work colleagues were annoyed that I was asked to keep it quiet (I will go into further detail in relation to this below). Therefore, when I moved to GRO-C I decided to be open about it -

I knew I would have to take time out of the office to attend the hospital for treatment.

- 30. Thankfully the combination treatment worked and there has been no viral activity in my blood work since. I continue to have regular blood tests to check for this.
- My mental health at the time and now is generally good. As far as I am 31. concerned, I am being monitored and I have cleared the Hepatitis C virus. The care I receive from the Royal Hallamshire Hospital is first class. However, in 2002, there was a very sad event which did have an impact on me. My cousin died and he is the only other member of the family with haemophilia, apart from my brother. I was at the Royal Hallamshire Hospital attending an appointment, I was reading The Haemophilia Society magazine and I came across an obituary for my cousin which I think his wife wrote. It struck me that he had contracted Hepatitis C, he had received the same treatment as me but it had not worked and he had gone on to develop liver cancer and died. That really brought it home to me that what I had could be fatal. From that day on, there has been a concern at the back of my mind although I do not dwell on it. Every time I go for an ultrasound of my liver, I am nervous waiting for the result and to be told that everything is fine. This is better now because I get the results of the ultrasound at my clinic appointment on the same day but previously I had to wait a few days. Nevertheless, it still does cause me some anxiety.

How infected status has impacted on medical treatment and/or dental care

32. I had to inform my dentist about being in the 'at risk' category in relation to vCJD and my Hepatitis C status but it has not impacted upon my dental treatment or any medical procedures which I have subsequently undergone.

Family/private life

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33. When I met my second wife, I had to tell her that I was a haemophiliac and that I had been tested for HIV which was a very hard thing to do. I had to explain that whilst I had tested negative, no-one was sure whether there was a chance it could still develop as the incubation period was not known. GRO-C

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Stigma

- It was during the period 1982 to 1986 that the AIDS crisis became a national 34. issue and the Government publicity campaign began. This had a big impact in the Southampton area as it became public knowledge that a young haemophiliac boy, who was HIV positive, who was going to be admitted to a primary school close by. A private meeting was arranged for the parents at the school with consultants in attendance from St Mary's Paddington, Southampton General Hospital and Local Authority education officers. The purpose was for them to explain the implications of the boy's attendance at the school and the precautions to be taken for the safety of all pupils and staff. As this school was close to my ex-wife's school, she arranged for me to attend and listen. This was a frightening experience for me as the hysteria amongst a few parents was palpable despite all of the reassurances given. Some parents were adamant that they would remove their children from the school if the admission did take place. I do not know the final outcome but it was very clear to me that if I had been infected with AIDS, my teaching career would have come to a sudden end as the parents at that time would not countenance such an infected person coming into close contact with their children.
- 35. I also had conversations with teachers at my own school as they knew that I had haemophilia and had, just before starting at the school, been in hospital and had been treated for a bleed that had kept me off work for a significant time. They were aware of the primary school case referred to above and some were adamant that they too would not allow their children to attend a school with a known case of AIDS. When I referred to my own situation they were less clear, but the doubt was clearly there. Several years later talking to my ex-wife, she commented that during this period I was notably stressed and very touchy

about anything related to AIDS. I did not appreciate at the time how I was being affected by the situation and the impact it was having at home.

- 36. As part of the process of joining the Local Education Authority in Hounslow, I had to undergo a medical examination which was carried out by my GP at the time. To me, my haemophilia was not a problem and I had always been open with everyone about it so I was not concerned about disclosing it but I was surprised that I was asked if I had been tested for HIV, which I had been. The results of my medical examination came back and I eventually received a letter confirming the job offer in Hounslow but, as I have referred to above, in that letter I was advised me not to tell my colleagues that I had haemophilia. This was the first time I was ever told not to disclose my haemophilia as my parents had always taught me to let people know, just in case anything happened.
- 37. I did not inform any of my new colleagues that I was a haemophiliac. However, eventually in a meeting with my immediate manager and representatives of the Regional Blood Transfusion Service (discussing a possible campaign in schools to raise awareness of becoming blood donors) I had to admit that I would not be accepted as a donor because of my haemophilia. My manager was appalled that I had not informed her of this and insisted that my immediate colleagues be informed for my own safety a reflection of my own previous situations. In telling my colleagues I also had to tell them that I had been tested for AIDS and was negative. This was especially difficult when speaking to Jane, who subsequently became my second wife.

Financial impact

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38. Other than post-surgery, I have had very little time off work due to my haemophilia, Hepatitis C or the treatment which I received for it and it has therefore not had any impact on my income.

Section 6: Care and support

39. I have never had any formal counselling in relation to my diagnosis with Hepatitis C or in relation to being tested for HIV. I do recall that when I had the

first HIV test, it was explained to me what that could mean in terms of testing positive but as my test was negative, there was no follow up in relation to that. In relation to Hepatitis C, the clinical staff at the Royal Hallamshire Hospital have always been so friendly and supportive, I have never felt the need for formal counselling. They know exactly who I am, I am not just a hospital number and I am happy with the support I receive.

Section 7: Financial assistance

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- 40. I have received the Stage 1 and Stage 2 payments from the Skipton Fund, I cannot recall exactly when I received these payments or the exact amounts, but I believe that they were approximately £20,000 and £50,000 respectively.
- 41. In 2010, because I was eligible for the Stage 2 payment, I automatically qualified for the monthly payments from the Skipton Fund which I think were around £1,000 a month. More recently the monthly payments have increased to £2,390 per month which are distributed by the England Infected Blood Support Scheme. I took voluntary redundancy in January 2010 and the payments which I receive allow myself and my wife to have a reasonable standard of life.
- 42. The application process for the financial assistance for me was very simple, partly because the medical report was done by the Royal Hallamshire Hospital and I believe that Professor Makris was involved in the working party to set up the payment mechanisms. I just had to complete the first page of the application form, the hospital dealt with everything else and it went through smoothly.

Section 8: Other

43. After hearing evidence given to the Inquiry by number of clinicians about the research carried out into contaminated blood, I am angered by some of the decisions which were made by the Government. Sir David Owen said the right things about the UK becoming self-sufficient in blood products but did nothing about it and I think that has carried on. Having worked in local authorities and having heard the evidence provided to the Inquiry, I know that the vast majority

of decisions are taken based on finances and that is what I believe is being uncovered. The decisions were not taken on health grounds but on financial grounds.

- 44. Whilst I am happy that the Inquiry is taking place and that there is going to be a proper analysis of what happened and who took the decisions and why, it should have been done much sooner. I have been upset on a number of occasions when there have been Government announcements about the action it is going to take (whether financial or otherwise) in respect of contaminated blood, namely because it makes me and families who have lost loved ones continually relive the past. It should have been dealt with a long time ago. The continual re-living of the past causes anxiety and upset to everyone impacted which angers me.
- 45. When I was diagnosed with Hepatitis C, my mother was very quick to say that it was her belief that no doctor would ever do anything that would be detrimental to my health and it has been a shock to discover that we were not being protected or at least provided with the information that the Government/clinicians did know.
- 46. I am prepared to provide oral evidence to the inquiry in public should I be asked to do so.

Statement of Truth

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

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Dated: 0-8 - 11 - 21