Witness Name: Andrew Nevin
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Exhibits: 0
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INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANDREW NEVIN

Section 1. Introduction

I, Andy Nevin, will say as follows: -

1. I live with my wife GRO-B in GRO-C and our two children, aged 13 and 10. I used to be a plumber but am no longer able to work due to my health. GRO-B is a full-time primary school teacher.

Section 2. How infected

2. I have Haemophilia A of mild severity.

3. I was tested for haemophilia at 12 years old but the result came back negative. I was tested again when I was 16 because my brother had been recently diagnosed with haemophilia. That test came back positive. My brother has

more severe haemophilia than I do. He suffers with more spontaneous bleeds. As a child I was prone to nose bleeds but not of the severity my brother had.

4. I was registered with the Royal Haemophilia Centre, Liverpool ('the Royal'), but cannot recall the name of my consultant at that time. I have been with the same centre throughout, and today it is called the Roald Dahl Centre and my consultant is Dr Toe.

5. I believe I received infected blood products when I was 16 or 17 in around 1980 or 1981. At that time I had a minor bleed into my knee and my mother took me to the Royal for treatment with Factor VIII. I refused the treatment but the consultant told me I had no choice because I was still an adolescent. They asked my mother to give permission for the treatment, which she gave.

6. At that moment in time there was the upsurge in the AIDS scare and there was a known connection with haemophiliacs and AIDS. I had a cousin who had recently contracted HIV and HCV, though he only knew he had HIV at the time. This was very concerning to me. I made the personal choice to refuse the treatment, but this was overridden by the consultant and by my mother.

7. I received Factor VIII at the Royal and was immediately discharged home: there was no inpatient stay. I vividly recall that I had a severe allergic reaction to the treatment, which almost killed me. It started with occasional vomiting which became constant. I was unable to keep any food or fluid down. I suffered with constant diarrhoea and developed jaundice. I was only awake for about two hours each day and recall only the beginning and the end of the illness, which lasted between ten and 14 days. The rest of the illness is difficult to recall as I was not lucid.

8. My mother was very concerned and rang the haematology department. She told them how I was but they were adamant it was nothing to do with the Factor VIII. They simply didn't want to know. They advised her to take me to the GP.

I went to the GP with by mother and was given medication, including antibiotics, to try to stem whatever it was. It eventually resolved after the two weeks of illness.

9. After that experience, and the fear around AIDS at that time, I went on treatment strike. I decided I would refuse any treatment with Factor VIII until it had been proven to be heat treated. This did not happen for another ten to 15 years and I didn't have treatment in all that time.

10. When I was given the Factor VIII, as described above, I was not given any information or advice about the risk of being exposed to infection from blood products. In fact, when I objected to having treatment, I was told all the blood had been tested and there was nothing to worry about.

11. Many years later I learnt that I had been infected with Hepatitis C (HCV). It has since come to light that I am at risk of vCJD. I was never told about this directly, but when I went into hospital for minor surgery I was the last person on the theatre list. When I asked why I was told that there was a risk of vCJD, which was never mentioned to me before. When I asked how they knew that about me I was told that I had previously been tested for it. I have never consented to being tested for vCJD and understood that there is no test for vCJD, so I remain confused and concerned about how this could have been tested for.

12. I found out I had been infected with HCV as follows. During my treatment strike my brother continued to receive care and treatment at the Royal. He had bi-annual checks and, during one of these checks, he was told he had HCV. My mother rang me and said that she thought I needed to get tested because of this.

13. So, for the first time in ten or 12 years, in around 1994 or 1995, I made an appointment to see the haematology department. When I arrived a nurse took

my blood. When I walked into the consulting room I saw the head haematologist and one other, which was strange, because at previous appointments there had only ever been one haematologist present. I was greeted with, 'we haven't seen you for a long time, we had you down as dead'.

14. We went through all the usual questions, with them asking about how I had been, etc. At the end the consultant said he thought we were done and both doctors started to leave the room. I asked whether they had anything else to tell me, to which they replied, 'no'. As they were walking towards the door the head haematologist turned and said, 'by the way, we have told you have hepatitis C, haven't we?'. I ran across the room and shut the door they were about to leave through. I grabbed my notes off them. They protested, saying they had ward rounds to do. I told them the ward rounds could wait and that I wanted to go through this now.

15. I opened the notes, and they opened straight to the list of previous treatments. The consultant haematologist asked what I thought I was doing reading the notes. I told him they had my name on. He said to me that I wasn't allowed to read them, and, when I said I could, he told me I wouldn't understand them because of the medical terminology.

16. I looked at the list of treatments with Factor VIII and pointed to the one when I was 16 or 17 and said, 'there, that is when you gave it to me'. I explained I had had a severe allergic reaction directly after the treatment. The consultant told me I couldn't say for certain that that was it and I told him I knew it was because of the reaction on my body at the time.

17. I have not had many treatments with Factor VIII. The only other treatments I had received had been for dental admissions. I have never experienced a reaction to Factor VIII like the one I experienced when I was 16/17. I know that is when I contracted HCV.

18. Although they had done a blood test that day, it had only been done at the beginning of my meeting with the haematologists and there was no way the results could have been available by the end of the meeting. They must have known from previous testing that I was HCV positive, and it was clear from the way they told me that they thought I already knew I was infected. I had not been seen at the centre for over a decade so they had been sitting on those positive test results all that time. I could have unknowingly infected a number of people during all of those years.

19. When I had received the treatment at around the age of 16 or 17, my brother had also received the same treatment within approximately two to three months. I believe we were both treated with blood products that were known to be infected. I believe we were used as guinea pigs; as PUPs (previously untreated patients). My last blood test, before I went on treatment strike, was around six to 12 months afterwards. I believe I would have tested positive for HCV at this time, but that result was never communicated to me

20. I was not given any information by the haematologists at that appointment in 1994/1995 to help me understand and manage the infection. I was given no information about the risks to others of being infected. When I left the consulting room a nurse approached me and was quite adamant that if I didn't have a liver transplant I would be dead in five years. I refused the liver transplant. I was also offered psychological support which I turned down.

Section 3. Other Infections

21. I have been infected with HCV as a result of being given infected blood products, and I believe I have also been exposed to vCJD.

Section 4. Consent

22. I believe I have been treated without my knowledge, consent, without being given adequate or full information and for the purposes of research. The best way I can describe how I feel is to say I have been treated as a lab rat.

Section 5. Impact

23. The impact on me of finding out I was infected with HCV was tough. I retreated from life and shut myself away. I disconnected from the world. I went into a downward spiral which was triggered by finding out about the infection and the liver nurse telling me I would be dead within five years. I lost control. Anything I earned I squandered. I lived as if I would be dead tomorrow. This went on for about a year.

24. I now suffer from depression from time to time. My wife, GRO-B, has also made a statement and she is able to describe this better than I can.

25. In terms of medical complications and conditions arising from the infection, I may have possibly developed heart arrhythmia as a result. There are studies in America which link heart arrhythmia with HCV, but none of my doctors will confirm the link. I cannot have major surgery as a result of the problems with my heart so if anything were ever to go seriously wrong I would not be able to have an operation.

26. I have developed early onset arthritis in most of my joints which I believe is as a result of HCV. I don't sleep well, and I am not sure if this is insomnia, depression or pain from my arthritis, or a little of all three.

27. I have declined all treatment for HCV. I was offered a combination of Harvoni and Ribavirin. When I researched these drugs I found that they cost the NHS £35,000 for a course of treatment. My liver nurse told me that, because I had

declined treatment so many times due to my heart condition, they would offer me a revised treatment plan which would be better than Harvoni and Ribavirin. The revised treatment would be a combination of four drugs over the same period of time. I said I thought I was being offered this because it was a cheaper option. She said no, that it was a dearer option. She then looked it up on her computer and apologised, saying that in fact it was £12,500 for a course of treatment. I explained to her that it was also cheap treatment that led to my infection with HCV in the first place. I have continued to refuse treatment. I have also refused the option of a liver transplant.

28. My brother has received treatment for his HCV. He was told there were no side effects but I have seen him suffer terribly. I also understand from others who have undergone treatment that there are psychological side effects with the treatment drugs, even though I have been told by doctors there are no such side effects.

29. I have questioned the terminology used about 'treatment'. My brother has been told he is totally clear of HCV. He was told his viral load has gone right down. I looked up what viral load means, and it doesn't mean you are totally clear of it: the bar can be set at a certain percentage. Even if you have just 1% of viral load you are still at risk of the virus potentially coming back. I told my brother what I had found. He went and questioned the consultant but couldn't get any answers.

30. I have had two liver scans. The first was around four years ago and the result was around 10.4. The second scan result was 14.4. That is still not high enough for a Stage 2 payment (see below).

31. I have not been involved with the infected blood community as a whole until I attended the opening ceremony to the Inquiry in September 2018. People approached me to exchange experiences. Some asked what treatment I have had and couldn't understand when I said none: some were on their first or

second liver transplant and looked much older than their age. When I came back from the Inquiry hearing, my overwhelming feeling was a sense of continued betrayal: that the whole haemophilia community is still being used as a test bed for testing and treatment for the rest of society.

32. My infected status has impacted on my treatment and care. I am constantly put under pressure to start treatment for HCV. I am routinely told, 'you are the last one in Merseyside'. They ask me, 'are you going to start treatment today? Why are you holding out? You are the only one in Merseyside who has refused treatment for HCV'. I feel the pressure. My wife does too: she now refuses to come with me to appointments as the last time she came they directed their questioning at her: 'you have two young daughters, do you want to see them grow up? He won't be around to see that happen.'

33. The impact of HCV on my private, family and social life is as follows.

34. I have always been honest and open about my infected status. When I met GRO-B I didn't want to tell her about it but I had to. Before I could ask her to marry me I had to first ask her whether she wanted to stay with me knowing what I knew. I also had to suffer the humiliation of explaining the virus to her parents when I met them.

35. Socially, it used to be difficult, but I don't think there is as much impact any more. Everyone knows I have HCV, so it is no longer such a cross to bear.

36. When I first discovered that I had HCV I felt stigmatised. People assumed that because I had HCV, I had AIDS. People would physically take a step away from me. I had a friend from childhood who once started a conversation with a group of our friends about why all haemophiliacs had got AIDS. I said I had haemophilia but I hadn't got AIDS, I had HCV. It stopped the conversation dead: you are a pariah. Attitudes are changing now that so many people are

coming forward. There is less stigma attached to HIV and HCV. There is a new attitude of, 'take these pills and it will go away'.

37. HCV has affected my working life greatly. I was employed as a plumber at the time I found out I had been infected. However, I lost my job when my life spiralled out of control after I found out I had the infection. I continued working on a part-time, self-employed basis until around five years ago when I had to stop work. I suffer brain fog and can no longer organise myself or my paperwork and cannot concentrate. I would do jobs and then forget to chase for payment so I would end up out of pocket as a result. Once the physical joint pain started I was unable to continue.

38. Financially, HCV has had a great impact on my life. I can no longer work and have not been able to provide for our family. I have not been able to put money aside for a pension so I have nothing for later life. We have not been able to maintain the house to the standard I would like and the girls do not have a nice home to invite friends back to. We almost lost our house and it was only because my father stepped in at last minute that we have been able to keep it. We have had to beg and borrow when our vehicles break down. At times we have been living hand to mouth. We can afford few holidays or days out, that has all gone and we just have to use what money we have to pay the bills.

39. My infection has impacted on my mother's life. She has never been able to forgive herself for giving permission for me to have the treatment against my will. My father was very angry about it but unable to talk to me. Our children have been affected in that I have not been able to provide them with the opportunities I would have liked to. We have had to say no to so many things, a new bike, gym classes, dance classes, swimming lessons. I feel it has impacted on their life chances for the future.

Section 6. Treatment/Care/Support

40. I feel my care and treatment has been delayed as a result of my infection. I was diagnosed with heart arrhythmia three years ago and was told the waiting list to see the consultant was six months. I have just received an appointment to see the consultant in six months' time, a delay of three years.

41. As described above, I was offered psychological support when I first found out I had been infected with HCV, but I turned this down.

Section 7. Financial Assistance

42. I received a phone call from the Caxton Fund out of the blue and they asked whether I knew I was eligible for payments and whether I wanted them. I said yes. A few months later my brother told me about the Skipton Fund, so I applied to that fund too.

43. I have received the Stage 1 payment of £20,000 in 2005 from the Skipton Fund, together with monthly payments of £1,000 every three months and a winter fuel payment. I also received monthly payments from the Caxton Fund of around £260. Through the EIBSS we now receive monthly payments of £500, £1,000 every three months, and the winter fuel payment. When the EIBSS wrote to us we discovered that we should have been claiming for the children, but we have not been allowed to claim retrospectively for the years when we did not know this was possible.

44. When my brother's liver function went to 12.5 he received a letter from Dr Toe saying he was eligible for Stage 2, but his application was declined and he was told he needed a liver score of 15. My liver score has been creeping up to 15 for a while now but they refuse to give me liver function tests as they say it could damage my liver. As a result, I have not been able to apply for the Stage 2 payment yet.

45. We have applied for and received some discretionary payments over the years. You have to get three different quotes and, if granted, you might get a contribution from the fund but not the whole amount. It is a very long winded and not very nice process, you feel like you are begging, and it takes ages for the payment to come through. We had a broken bed on my wife's side of the bed and applied for a discretionary payment to buy a new bed. GRO-B had to sleep on the sofa downstairs for three years. I think they make the process intentionally difficult so that people don't apply again.

46. In order to receive the Stage 1 payment I had to sign a declaration saying I would not sue for anything else.

47. I do not feel there is equality with the financial assistance offered. England, Scotland, Wales and Northern Ireland each have separate regimes and individuals in different countries get different amounts for the same thing.

Section 8. Other Issues

48. I have tried to request my medical records. My GP surgery informed me that when I moved surgeries the previous surgery said they had no records for me and that I had never been registered. I now have to go and speak to the practice manager to try to get to the bottom of this. I have also been told my hospital records are missing, even though I have seen them myself in 1994/1995, as I have described above.

49. I have been lied to in the past and I feel I am still being lied to today. When I was diagnosed there were just short of 6,000 haemophiliacs in this country, and now there are just over 2,000 left. I feel like they are just waiting for me to die.

50. I hope the Inquiry is able to get to the truth of who made the decision to knowingly import infected blood, and what the government knew and when. I

want there to be an acknowledgment that information was withheld from haemophiliacs, who were subjected to research without consent.

Statement of Truth

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

Signed GRO-C

Dated ……22 February 2019………