Witness Name: Andrew Nevin
Statement No: WITN2785001
Exhibits:0
Dated: February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ANDREW NEVIN

I, Andrew Nevin, will say as follows:-

Section 1. Introduction

1. My name is Andrew Nevin, DOB GRO-C 1964 and I live at GRO-C GRO-C with my wife and two children.

2. I make this statement to the Inquiry in my capacity as a person infected with Hepatitis C as a result of treatment with contaminated Factor VIII concentrate.

3. My brother, Sean Nevin, has also given a statement to the Inquiry (WITN1425001).

4. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How infected

5. I was tested for haemophilia when I was 12 years old following a tooth extraction that bled heavily. The test came back negative. My brother was then diagnosed with haemophilia so they brought us both back in for testing. I was then diagnosed with mild haemophilia A at 16 years old at the Royal Liverpool Hospital.

6. I required very few treatments and lived a typical teenager's life; I played football, ran around, climbed trees and I never had a problem.

7. When I was 17 I was playing football on frozen ground and fell, injuring my knee and causing it to swell. My mum took me to the haemophilia department at the Royal Liverpool Hospital where I was told it needed treatment. I refused point blank to accept any treatment. However, because I was only 17 years old, the doctor asked my mother who gave permission for me to be treated. This was the first time I received Factor VIII concentrate.

8. I had an allergic reaction which shut down my liver and I became unwell within 24 hours of treatment. Within 10 days my health had seriously deteriorated. I was only be awake for about two hours each day, during which time I was barely lucid.

9. The haematology department denied they had done anything wrong and I was taken to the GP, who prescribed me an array of antibiotics. Somehow, in time, I made a recovery.

10. After this incident, I stopped going to the Haemophilia Centre. I was told to go in for annual check-ups but I refused to go back as they had almost killed me. To this day I refuse treatment.

11. Some time later my brother went in for his annual consultation. After the consultation, just as he was leaving the building, his consultant casually said 'oh by the way you have Hepatitis C'. After this, my mother advised me to

make an appointment, so I scheduled a meeting at the Haemophilia Centre for the first time in around ten years.

12. When I arrived, I was greeted by the head haematologist and one of his juniors. The conversation started with them saying 'we haven't seen you in a long time; we had you down as dead'.

13. It all appeared to be a very normal consultation. They took my blood and sat me down for a conversation but at no stage did they mention Hepatitis C. When things were coming to an end, I asked them point blank if they had anything else they wanted to tell me. They said no.

14. As I got up to leave the room, they did exactly the same thing they had done to my brother. As I was half way out of the door, one of them said 'oh have you been told you have Hepatitis C?'. As they had already used this technique on my brother, I put my foot in the door and refused to let them kick me out. I forced my way back into the consultation room and told them to sit down.

15. I took my medical records from the hands of the consultant. He told me that I wasn't allowed to see them. I said 'I can, they're my records'. As I had received such few treatments, I put my finger on the treatment which caused the reaction and said 'that's when you gave it to me'.

16. They told me very, very little about the prognosis of the infection or its possible routes of transmission.

17. They must have been aware of the fact that I was infected for a considerable amount of time as I had not set foot in the haemophilia department in about ten years.

Section 3. Other Infections

18. I was only made aware of a potential risk to vCJD fairly recently when my brother went into the hospital for minor surgery. He was told it would be done at 9am, but he was made to wait until 5pm. When he asked why, he was told it was because of his vCJD risk.

19. When I next saw my liver nurse I therefore questioned her about it. She told me that I had nothing to worry about as I had tested negative for it, however to my knowledge, there is no test for it and no testing was every discussed with me in any event.

Section 4. Consent

20. I had no idea that I had been tested for Hepatitis C, let alone the fact that I had tested positive. I think my brother and I were used as guinea pigs as we were easy targets. We were clean slates who had never received treatment.

Section 5. Impact of the Infection

21. Physically, I am tired all of the time. I suffer from joint pain and muscle aches, and just a general sense of fatigue.

22. Psychologically, it shattered me when I first learnt that I had Hepatitis C. It put me in a very dark place. I lost the next ten years of my life to depression and self-destruction that was brought on by the news of my diagnosis.

23. At the time of my diagnosis I was a plumber. I then went self-employed as I was not in the right place to be able to work for an employer because they wouldn't have understood what I was going through. I managed to work for a while, but if I attempted to work for more than three days I would just be physically exhausted. It's impossible to live on three days work. Financially, I haven't been able to do what I wanted to do with my life. My wife is now the main breadwinner and I am a house-husband.

24. I met my wife in 2001. It was nerve wracking having to tell her about my Hepatitis C, but fortunately she was extremely understanding.

25. We researched the possibility of having children and eventually decided that it was a risk worth taking. The first thing the hospital did when my wife found out

she was pregnant (and later when she gave birth) was to take a blood test. Thankfully, both of our children are clear.

26. I have been encouraged to undergo treatment to cure my infection. I was told by doctors that there are no side effects to Harvoni, but having spoken with people that have taken the drug (including my brother) I know there can be horrible side effects. I was also told that 100% of people they had treated with Harvoni had been cured. I questioned them on this statistic so they then told me it might be more like 90%, and then later that it was probably more like 85%. I don't understand why they can't just be honest with me when discussing my treatment options.

27. I have been diagnosed with Arrhythmia. When I was looking into the potential side effects of treatment for Hepatitis C, this also happened to be the most common side effect. I therefore refused to take any medication until I had spoken with a cardiologist. When I spoke to my cardiologist at Southport Hospital, he told me that he had never been provided with my records from Liverpool. There is no joined-up care and this has been going on for years.

28. I have had two Fibroscans. My first scan three years ago scored 11.4 kPa, however they keep telling me different results from my second test. The results from the second test came up on the screen as 14.4 kPa, but they later told me that it was actually 10.2 kPa, and when I returned for a later appointment they told me another figure altogether. I don't understand how they have given me three different results for one test.

29. I have asked for another Fibroscan but the hospital has refused. I request one at every appointment but they refuse, as they say that doing further scans could cause more damage to my health. I am unaware of how these tests can have a negative effect on my health.

30. I was originally told that if I didn't have a liver transplant in five years time I would be dead. I refused point blank. I have talked to numerous people who were infected with Hepatitis C and pressured into transplants. Most of them

seem to have complications and more health problems, and regret being pressured into a transplant.

31. The impact on having both sons infected tore my mum apart. She broke into tears one day as she felt so guilty for making me have the treatment when I was 17. She has felt guilty her entire life.

32. My wife just gets on with it. We have a separate shelf for my toothbrush and razors and we have to tell the kids to stay away from me if I cut myself.

33. Initially I had some problems with the stigma of being a haemophiliac due to the link with HIV and Hepatitis C. Now most of my friends know and I don't let the stigma bother me.

Section 6. Treatment/care/support

34. I was offered counselling after my diagnosis but I refused it.

Section 7. Financial Assistance

35. I was approached by the Caxton Foundation who told me that I may be eligible to claim some payments.

36. I received the Stage One lump sum payment from the Skipton Fund.

37. When the funds were merged to EIBSS, my wife calculated that I would lose half of the money I received from them because her salary was increasing. They later sent paperwork out which suggested I could claim for my children also, but I had never been told this before. As I am now able to claim for my children, I receive the same amount I was receiving before my payments were cut due to my wife's pay rise.

Section 8. Other Issues

38. I want to find out who made the decision to use people as human guinea pigs.

39. I want answers as to why it took them nearly 20 years to inform some people they had been infected.

40. It is my belief that the pharmaceutical companies paid the hospitals to test their drugs on us, and I would like this investigated by the Inquiry.

Anonymity

41. I do not want to be anonymous.

42. I would consider giving oral evidence to the Inquiry.

Statement of Truth

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

Signed...... GRO-C ....

Dated 27.2.19