

Witness Name: Neil Clayton
Statement No: WITN2891001
Exhibits: WITN2891002-003
Dated: 01 May 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF NEIL CLAYTON

I, Neil Clayton, will say as follows:-

Section 1. Introduction

1. My name is Neil Clayton. I was born on GRO-C 1981 and I live at GRO-C
GRO-C.
2. I am currently unemployed as I am sick. I have two children, a son who is 5 years old and a daughter who is 1. I am cohabiting with my girlfriend.
3. 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

4. I suffer from severe Haemophilia A and I was diagnosed approximately 4 or 5 months after I was born.
5. I was initially given blood transfusions and later I was given Factor VIII concentrate (FVIII) to treat my haemophilia. From the age of 8 years old, my

parents started to administer FVIII to me at home. They were trained by the nurses at St James Hospital (SJH) in Leeds.

6. I have always been treated at SJH. In the early 1980s, I was under the care of Dr Swinburn and Dr McVary but I believe that they have both retired now.
7. My parents were my main carers when I was a child. I do not believe my parents were provided with any information or advice beforehand about the risk of being exposed to infections from FVIII concentrate.
8. I was infected with Hepatitis C (Hep C) as a result of being given FVIII concentrate.
9. When I was about 16, I attended a routine appointment with my parents. It was at this appointment that I was told that I had tested positive for Hep C. After reviewing the limited medical records that I have, I found a blood test, dated 23 November 1994 which shows that I had a blood test but I was not tested for Hep C because I had previously tested positive for it. This shocked me as it seems that I have had numerous tests for Hep C prior to being told when I was 16. A copy of the blood test is exhibited at 'WITN2891002'.
10. The doctors told me that everything was fine and not to worry about the Hep C. They really downplayed the infection at the time as if it was nothing. I had a girlfriend when I first found out about the Hep C and I was not told anything about passing it on through sexual intercourse and saliva. I believe such information should have been communicated to me.
11. I do not believe we were provided with any relevant information about the infection at the time. I was never told that I was going to be tested for it. However, I was told by the doctors at the same time that I had immunity to HIV as I was given the same batches of treatments that others received who were infected with HIV. I was told that the test for HIV was negative. I was not aware that I was also tested for HIV.

12. I believe that my parents and I were not given adequate information to help us understand and manage the infection. I believe the hospitals were more concerned about covering everything up at the time.
13. I believe that information should have been provided to me and my parents earlier, when the doctors first found out I was infected.
14. When I was about 17/18 years old I started to do my own research and found out information regarding the risk of others being infected as I was not provided with any information by the doctors. I told the doctors that I had a partner and asked what the risks were, they said there were no risks and that Hep C was nothing to worry about.

Section 3. Other Infections

15. As a result of the Hep C, I suffered from osteoarthritis, depression and rectal bleeding.
16. In or about the early 2000s I received a letter stating that I was at risk of being exposed to vCJD. I had a follow-up appointment with the doctor who told me that they had to inform everyone about the risk as a precaution. I felt sick when I found out because I could also have vCJD on top of all the other conditions that I have as a result of being given contaminated blood products. This was too much for me to handle at the time. It plays on my mind even now and I am upset by what I read as vCJD attacks the brain. I will never know if I also have this condition.

Section 4. Consent

17. I believe that I was treated and tested without mine or my parents' knowledge and consent. I did not know that I was being tested for Hep C or HIV at the time. However, after reviewing my limited medical records, I believe that I was tested for Hepatitis B (Hep B) in 1984, which was positive, I was tested for HTLV-III in September 1985, which was negative and I was tested for Hepatitis and HTLV-III in November 1985 and both tests were negative. The above test and letters are exhibited at 'WITN2891003'. I have since had

regular tests for HTLV-III and I was never told about them. I believe that further tests were carried out after the above tests, however, I am unable to prove it because I believe that a lot of my medical records are missing.

18. I believe one hundred percent that I was treated and tested without being given adequate or full information. Even if my parents were told about a small risk relating to the FVIII concentrate, they would not have agreed for me to be treated with it.

19. I believe I was treated and tested for the purposes of research. I believe that a lot of us were used as guinea pigs. The hospitals also put everyone on different drugs in order to trial and error it.

Section 5. Impact of the Infection

20. I suffered mental effects as a result of being infected with Hep C. I suffered from depression during my teens which became worse following the treatment that I had. At one point, I tried to kill myself using a knife. It was really out of character. I also started to have suicidal thoughts on a regular basis. Prior to the diagnosis, I was a very happy person but post diagnosis, I started to feel very down. I had never felt miserable like that ever before in my life. I thought I was going to die. I saw a psychiatrist who told me to take anti-depressants, which I have been taking on and off for a while. I had to go seek treatment for my depression myself, it was not offered to me. After taking the anti-depressants, I started to feel more like myself but the Hep C left a long term effect on me. I was always a smiley person before diagnosis.

21. I also suffered physical effects as a result of the Hep C. I became very skinny and was yellow and pale all the time. I also had anal bleeding and the doctors could not find what was causing it. However, from my research, I found out that anal bleeding is a symptom of Hep C. I also had nose bleeds randomly, something which I never had before. I lost a lot of weight and hair and I also had tiredness and was fatigued a lot of the time. I was told that I started to develop cirrhosis, but it did not get to the serious stage as the treatment cleared it. As a teenager I was finding it difficult to put on weight and I believe

it was because of the Hep C. I found this to be unusual because my family members are very well built. I looked like a skeleton. After I had completed the treatment, I started to put weight on and started to feel normal again.

22. In or about 2003, I was given PEG Interferon and Ribavirin treatment. I was told that the course was for 48 weeks. After I completed the course the doctors confirmed that the treatment cleared the Hep C. I was given little information about the side-effects.

23. I believe there were other treatments which ought to have been made available to me, but were not. I now know that there were drugs for Hep C, which consisted of taking a tablet daily. I read that the success rate was high, with minimum side-effects. However, I was not offered this.

24. The treatment caused me to suffer mentally. It once caused me to almost jump out of the window but my father pulled me back and saved me. I did not even know that I had tried to climb out of the window until my father told me. I was mentally unwell at the time.

25. The treatment also affected me physically. It felt like someone was hammering my bones all the time. I would inject myself on a Friday and it would take until the next Thursday for me to feel a little better, only to inject myself again and feel horrible again. I felt like I had flu 24 hours a day, 7 days a week, I just could not shift it. The above symptoms continued throughout the course of the treatment. I found it extremely difficult to do any normal day-to-day activities. I had physiotherapy as I became so fragile. The treatment also affected my appetite I was unable to keep anything down and as a result I lost a lot of weight. Every aspect of a normal life was affected.

26. My infected status impacted on the medical care that I received for other conditions. People that knew I had Hep C treated me like I was dirty which made me feel awful. Nurses and medical professionals were scared about being contaminated. My dental procedures were delayed due to the Hep C and I would be last in the queue all the time for any dental treatment. It made me feel very dirty and like a lesser person which affected me psychologically.

I was very paranoid and my self-esteem was lowered. In the mid 2000s I had problems seeing a local dentist and I believe it was because of the Hep C.

27. The Hep C also impacted me on my private, family and social life. I was in my early adulthood when I was diagnosed, and I missed 2 years of enjoying life and going out with friends. I did not really have a social life at the time, especially when I was on the treatment. I was isolated and I was very withdrawn. My family was devastated to see me like that.

28. There was a stigma attached to Hep C at the time. Whenever the doctors and nurses treated me, they made it a big deal and used gloves around me. I was very hurt by this but I understood that people did not want to be infected themselves and so I do not blame them. It was embarrassing when they talked out loud so that everyone could hear that I had Hep C. When I was about 16 years old, my nose was bleeding and the teachers were telling other students not to touch me and that they would get gloves. It was devastating to be treated like that.

29. The Hep C had an educational effect on me. I was so worried at the time that I could not focus on my studies. Thinking that I was going to die, made me not care about what results I would get in my exams. I did do my GCSEs but the results were no where close to what I could have got had it not been for the infection. When we went on trips and I cut myself, my friends would make a massive deal out of it which made me feel horrible. I did go to college, but I believe that I would have done better had it not been for the infection.

30. The Hep C had work-related and financial effects on me too. When I was in my teens I had a part-time gardening job, but when I started to feel the Hep C symptoms, I stopped and did not get to go back to that job. When I was about 19/20 years old I trained to become a vehicle paint sprayer and was on a salary of about £20,000. This was a very good salary for someone who was quite young at that time. I had to take time out from the job for my treatment. I did return to that job but eventually gave it up. I wanted to pursue it as a career but could not.

31. The infected status also impacted my parents. They were devastated to see me ill. I looked like a little skeleton with my life sucked out of me. It was very hard for my mother as she was the one who administered FVIII to me since I was a child.

Section 6. Treatment/care/support

32. I believe I faced difficulties in obtaining treatment, care and support as a result of the infection. I was given physiotherapy and hydrotherapy by the hospital, but I believe I should have been given treatment a lot earlier.

33. I was only offered counselling twice as a result of what happened to me, but it did not help. I was just given medication and left to deal with it. I believe I should have been offered more treatment as it would have helped. The doctors should have told me pre-emptively about the side-effects of the infection and the treatment. I tried to stab myself once and I believe counselling would have prevented me from having suicidal thoughts. I believe I should have been offered counselling when I first tested positive.

Section 7. Financial Assistance

34. I received the Stage 1 payment of £20,000 from the Skipton Fund when they first started paying out but I cannot remember exactly when this was.

35. My monthly payments started last year and I receive £1,500 a month and £400 extra as I have two children, but this is means tested each year. Recently, I received a backtracked amount of £7,000, but this does not add up to what I missed over the past 20 years. The applications are very long and difficult and it feels like I am begging from them.

36. I found out about the trusts and funds myself. I paid £300 just to get my medical records and 4 months of hard work just to prove I was truly infected and affected as a result in order to show that I was entitled to the payments. The government makes you beg for money and makes it seem like you are faking the symptoms, which I believe is wrong. The process is so complicated. You could get more money but you have to pass through a

hundred hoops before you even pass the first stage. They have an illusion that you can get more financial assistance but in reality it is quite difficult to get the finance assistance that you are entitled to.

37. I have a letter stating that if I had cirrhosis I would have been entitled to the Stage 2 payment from the Skipton Fund. However, although I started to develop cirrhosis it cleared with the treatment and therefore I was not entitled to the Stage 2 payment. I believe it was their loophole not to give me the Stage 2 payment even though I had started to develop cirrhosis, it was not enough for them. I went on a horrible treatment that ruined my life, and it is unfair that I could not get Stage 2 payment. If I never had the horrible treatment, I probably would have died. It took me absolutely ages to apply for the Stage 2 payment, but I got nothing from it.

38. I believe it was unfair that other people received up to £50,000 from the Skipton Fund and are also receiving another £2,000/3,000 a month for the past 20 years or so, but I received a lot less and only just started to receive the monthly payments. I believe we should have all received the same amount of compensation as we were all infected.

Section 8. Other Issues

39. A lot of people who were given same batches of FVIII as me have died as a result. It really upsets me. I just want justice.

40. I would like answers as to why the government allowed all of this to happen.

Anonymity, disclosure and redaction

41. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

42. I wish to give oral evidence at the Inquiry.

Statement of Truth

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

Signed.. GRO-C

Dated 01/05/2019

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

Virology Results

02.09.1994	Antibody to HIV – 1 or HIV – 2: not detected
23.01.2004	Hep C RNA by PCR – Negative
21.10.2004	Anti HBs detected
12.08.2013	Anti HBs detected

Significant Entries

04.10.1984	Letter from L M Swinburne to Dr Houghton – this boy's hepatitis b vaccination course was completed 5.12.1983. he has had minimal bleeds since last seen with very few joints involved. He will be seen again at the clinic in a year's time.
02.03.2006	Letter from Angela Westoby to Acute Dental Clinic – he is Hep C and HIV negative and has been vaccinated against Hep B. he has however been exposed to UK plasma products in the past and is therefore, for public health purposes at risk for vCJD. Neil has had difficulty securing a dentist outside the hospital and is currently experiencing some toothache....
11.09.2007	Letter to Dr Houghton from B A McVerry – I saw this young lad with haemophilia again today. Mood wise he seems very much better and not nearly as depressed as before.
25.10.2012	Letter to Dr Lightfoot from Dr Lishel Horn -he feels as though he is getting quite depressed at present and did seem in

low mood today. He has self-harmed in the past when he was depressed and I have therefore asked him to consult you as soon as possible about his mood problems....