

Witness Name: LEE ANTHONY COVERDALE

Statement No: WITN3220001

Exhibits:

Dated: May 2019

## INFECTED BLOOD INQUIRY

---

### FIRST WRITTEN STATEMENT OF LEE ANTHONY COVERDALE

---

I, LEE ANTHONY COVERDALE will say as follows:-

#### **Section 1. Introduction**

1. My name is Lee Anthony Coverdale. I was born on the GRO-C 1977. I live at GRO-C, Essex, GRO-C. I am married (since 2003) with one step-son, who is 28 years old. I work part time as a driver, when I feel well enough.
2. This witness statement has been prepared without the benefit of access to my 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**

3. I was diagnosed with Haemophilia B (Christmas disease) when I was 18 months old. My mother said that I had lots of bruising and was crying a lot so they took me to the doctors. The doctors took my mother and father aside as they suspected I was being abused. However the blood test diagnosed that I was a Haemophiliac.

4. I do not know the exact name of the products I received but it was Factor IX (FIX). My mother used to keep a diary in the 1980's of all the occasions that I had a bleed. At the age of 10 years old her diary showed that I had 55 bleeds in that year. I think my mother still has this diary.
5. I think I attended Great Ormond Street Hospital for care when I was very young. My main Haemophilia Centre used to be at Whitechapel Hospital, under the care of Dr Colvin. I would attend Whitechapel Hospital for appointments and serious bleeds. If I had day to day bleeds I would attend Broomfield Hospital in Chelmsford which was my local hospital.
6. I believe I was infected in the 1980's but I am unsure of the exact date. I changed to prophylactic treatment in 1987 and I had injections once a week as a precaution which did help. In 1991 I started home treatment and my mother used to inject me at home. I started injecting myself in 2000 and I think I was injecting myself twice a week.
7. I have asked my mother and she does not remember anyone that may have talked to us about the risks of receiving contaminated blood. I think my mother believed I needed the treatment in order to survive.
8. I was infected with Hepatitis C (HCV) as a result of being given contaminated blood products.
9. I knew from about 18 years old that I had been infected with HCV. I do not remember being officially sat down and told directly about the HCV though. I do not remember having a test and I can't recall that I was shocked when I was told. I do not even remember ever having an appointment just about the HCV. The news was just thrown into a Haemophilia Clinic appointment. Whenever I went to the Haemophilia Clinic it was mentioned in a conversation.

10. My mother does not remember when the doctors told her I had HCV either. AIDS was all over the news but HCV was quiet. My mother said she asked if there was any chance I could contract AIDS and the doctors reassured her that the problem was with FVIII. I think I was 10 or 11 years old when this conversation happened.

11. I was informed that I was 'a carrier of HCV' and it might get worse in 30 years, but not to worry about it for now. I do not remember being given adequate information to help me understand the infection but I was very young. When my wife and I first got together she came to an appointment with me and she does not remember the doctors ever talking about HCV seriously. The only information I remember being provided with frequently was not to drink alcohol.

12. My wife used to ask about whether I could pass the HCV onto her but we were told that it was rare. We were not told about any precautions however in 2001 we were provided with a leaflet which talked about not sharing tooth brushes and razors.

### **Section 3. Other Infections**

13. I do not believe I was infected with any other infections.

### **Section 4. Consent**

14. I do not remember being tested for HCV and I cannot be sure that I consented to the test. I do remember being told that I was being tested for AIDS but I do not recall when it was just that I felt really it was a scary time. I had blood tests every time I went to an appointment so I could have been tested at any time.

15. I do not know if I was tested or treated for the purposes of research.

## **Section 5. Impact of the Infection**

16. The HCV caused me to feel tired and sick from a pretty young age. I used to moan when I was in my 20's but I believed I was depressed and my father thought I was lazy. However I was already suffering from the side effects of HCV.
17. Being diagnosed with HCV has had a massive impact on my mental health. I used to shut it away and keep it a secret. At 18 years old I was not going to tell anyone that I had another disease. It was only when I started getting taken in for scans on my liver and the doctors told me that I had signs of cirrhosis that it clicked in my head how serious it was.
18. Every year I went for an appointment and it was around 2003 or 2004 that a liver doctor would also attend with the Haemophilia doctor.
19. In 2006 I felt so tired and I swelled up with fluid. I now know this was because I had scarring on my liver. That is when the hospital brought me in for a meeting and said they wanted to start me on a clearing treatment trial.
20. The first treatment I had was in 2006 at Whitechapel Hospital. I cannot remember the name of this treatment but I injected myself in the stomach and then I would literally have to lock myself away in my bedroom to recover. I took the treatment for 3 months but I do not think it was successful and so the treatment was stopped.
21. I had horrendous side effects from the first treatment including depression, tiredness, and fatigue. I used to stay upstairs in my bedroom for months and all I wanted to do was give up. It is only that everyone would come in every day and make me get up.
22. About 6 months later I was spoken to about another new treatment. I believe the second treatment was interferon which I think I started between 2006 and 2009. During that treatment I had to go into hospital because my white blood

cells were too low and I had to have two blood transfusions. In the end I had to come off the treatment because it was too dangerous. I think there were signs that the treatment may have been working but I could not take it anymore.

23. I was told that I was a candidate for a liver transplant and I underwent lots of tests to make sure I was fit enough for the transplant. I went home and within days they telephoned me and stated that they had a liver for me. At that time I was seriously ill, down to 10 stone in weight and in intensive care.

24. I had the liver transplant in 2009 at Whitechapel Hospital under the care of Dr Foster. I was then transferred to the Royal Free Hospital and had to have two weeks there and within days I felt much better. Although I was swollen and yellow after the transplant my eyes instantly went bright white. It took me about a year to get completely back to normal.

25. As soon as I was back on my feet from the transplant I had to have more treatment for the HCV. So in 2010 I started the third clearing treatment under the care of the Royal Free Hospital. I cannot remember what the treatment was or how long it lasted for.

26. I experienced the same side effects as I had previously but it wasn't working quickly enough and I could not stand it.

27. I undertook the final clearing treatment in 2014. I managed to get on the list for a new treatment that only 500 people with the worst cirrhosis in the country were allowed to have. I managed to get the treatment and it lasted for approximately 4 to 6 months. Each time I went for the treatment my numbers went right down and then they finally told me that I was clear of the HCV.

28. However within 2 months of being cured of the HCV the doctors did a scan and said my liver was too damaged and I needed another liver transplant. I had cured the HCV but needed another transplant.

29. I was so ill waiting for the second liver. I would swell up with fluid in my stomach which was horrific. I was going to London once a week and having a big needle in my stomach to drain bags and bags of fluid, it would take hours. It was litres and litres of fluid every week. I also had toxins going to my brain which caused brain fog. I did not leave the house for 6 months other than to hospital whilst I was waiting for the transplant.
30. On more than on occasion I had been told that they had a liver for me. I would get ready for surgery, lay there waiting while they took the liver out of the donor, and then be told for one reason or another that the transfer could not go ahead. One time it was because the liver was not a match and the other was because the wife of the donor would not consent to the donation.
31. I came home one night in 2015 from having my stomach drained and I felt so ill. I was rushed to Bassledon Hospital by an ambulance and went into intensive care for about 3 or 4 days. Whilst I was there my doctor came over and told me that I was being transferred to the Royal Free Hospital as they had a new liver for me. I then went to London in an ambulance and had the liver transplant that night. When I spoke to the liver doctor after the operation he said I was so lucky because I would not have lasted another month without a new liver.
32. Since I had the transplant I have managed to lead more of a more normal life. However, I have a massive scar on my chest across both sides of my body. The scar has started popping and I have hernias all over my stomach. I was warned when I had the second transplant that it may cause me problems but I didn't have any choice I needed it to stay alive. It is not at all good but my whole insides are just hanging out and I only have a thin layer of skin that is keeping my inners in. Everything is hanging out the front and its giving me back pain. Even going out for meals now is uncomfortable, I need to recline and lay back to let my stomach settle. I cannot get any of my clothes on and it looks like I have an alien hanging out of my stomach.

33. I have to wear a corset to pull everything in. I had a small corset which caused sores and it got so deep fluid came out about a month ago and I spent a week in hospital. They then changed one of my tablets to help with the sores.
34. I am currently seeing a specialist at the Royal Free Hospital and they are going to operate on my stomach. I have had to wait for the operation on my hernias until I was fit enough. I need a mesh put into my stomach but I am told that it will cost £20,000 and I am waiting to find out if the board will approve the funding. The operation will involve cutting my stomach open and essentially pushing my organs back into place. I am told that I will be in intensive care for a couple of days after the operation because and I will not be able to breath for a couple of days. I am told that there is also an issue with my bowel and during the operation they need to be really careful with it, which is a little bit worrying but I cannot live how I do now. Once again I do not have a choice.
35. I also have had a few problems with the liver and I had to have a stent put in.
36. I actually feel pretty positive now. It is the best I have felt as I am now disease free. I am confident that my liver is working well and I do not have to worry that I have something eating away at it. I can finally plan things for the future. I just need to sort my stomach out and hopefully I can then move on.
37. Once I moved to the Royal Free Hospital I felt like I received really good treatment. I always thought because I received contaminated blood I have been pushed to the front of any queue because they felt guilty for causing a lot of my problems. I have met other people in similar situations who have waited much longer than me for a liver transplant.
38. I still do not tell people about my infections because of the stigma, people automatically assume you have it from drug abuse. Even now when I tell people I have had liver transplants they assume it must be because I drink a

lot. So if I tell somebody I then have to explain my story with regard to the contaminated blood.

39. I have only been able to cope mentally with everything that I have been through because of my family. If it were not for them I could have easily given up on so many occasions. Being infected has affected my entire family so dramatically. There were times when I was so ill and I would have to be taken to hospital and my family would have to carry me to the car and lay the back of the car seats down so I could just lay there.

40. My wife and I also had to sell our house and we had to buy a property with my mother and father because I needed help as my health was so bad. My wife and I had our own 3 bed bungalow in [GRO-C] but in 2006 we knew I was getting worse, so my mother and father sold their house. We also sold our house and we bought a property with my parents. My father was a builder so he split the house in half. My parents lived upstairs and we lived downstairs. Just before the second transplant we moved again and bought a bungalow. We are all helping each other now and I would not be alive if we did not all live in the same house. It was a team effort but my mother is 66 years old and my father is 74 years old and [GRO-C] they will not be able to care for me forever.

41. My wife and I tried for children [GRO-C] The stress of everything might have affected the [GRO-C] [GRO-C]. It is hard to know. My wife also had to deal with the prospect of growing old without her husband. We could not plan for the future. It was also worrying for me as I did not want to leave my wife financially unstable.

42. My mother has also been greatly affected by the way I contracted HCV. Because my mother used to give me my FIX treatment she worries that she is responsible for giving me an infected injection. It is something she will always carry with her.



43. My education suffered because of my Haemophilia. I would sit in the library in a wheel chair and one of the other children would bring work to me because I could not get up the stairs. I missed a lot of school too.

44. I have never really had a proper job because of my health. I could not work with the Haemophilia and then with the HCV. I have always lived on my disability allowance and a tiny wage. I drive when I can for a friend. Since my transplant I have not been able to do a full years work. It is only because I am lucky enough to have someone who has stuck with me that I could do any work at all. If I had to get a job somewhere else I would never be able to hold it down. There were times when I was driving and doing a delivery and I would have to pull over and be sick into a bowl.

45. My wife has never been able to work properly either. She gave up full time work as a manager of a shop to look after me. She had to come to the hospital every day and care for me.

46. We have had to re-mortgage the house each year so we are left with a bigger mortgage. Every year we borrow more and more money. I was lucky that I managed to get a mortgage as the 4 of us were on it.

#### **Section 6. Treatment/care/support**

47. I was offered counselling and I went once but it felt like it was not doing much to help me because they could not answer the one question I really wanted to know, which was whether or not I was going to live.

48. My wife was never offered any counselling.

#### **Section 7. Financial Assistance**

49. For the last two years I receive a monthly payment from the Skipton fund in the sum of £1,500 a month. Prior to that I received disability living allowance (which I still receive alongside tax credit). My wife receives a careers

allowance of £66 a week but when she was working she was on £200/£300 a week.

50. I received 2 lump sum payments from the Skipton fund in the sum of £25,000 and then £20,000.

#### **Section 8. Other Issues**

51. I believe it should have been made clearer to the public how Haemophiliacs became infected with HIV and HCV so other people know and understand why we had these infections. People just think you are a dirty drug taker or alcoholic because you had HCV. If the NHS came out and told the truth people would have understood but it was just kept all hushed. It all feels a bit shady, like they used us and let us get worse to see how long it would take for HCV to eat the liver. I want to know were we lied to and were we used as guinea pigs? I do not think anyone or even the Inquiry knows how much we have suffered until now. This affects entire families.

#### **Anonymity, disclosure and redaction**

52. I am not seeking anonymity. However I understand this statement will be published and disclosed as part of the Inquiry.

53. I do not wish to give oral evidence to the Inquiry as I do not want to bring extra stress into my house. I have enough to deal with my health and my poorly father.

#### **Statement of Truth**

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

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

Dated... 6/6/19.....

**MEDICAL SUMMARY**

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

This witness statement has been prepared without the benefit of access to my full medical records. .