Witness Name: J R Shackleton
Statement No: WITN1705001
Exhibits: 0
Dated: April 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF
JOHN RICHARD SHACKLETON

I, John Richard Shackleton, will say as follows:-

Section 1. Introduction

1. My name is John Richard Shackleton of GRO-C Lancashire, GRO-C My date of birth is GRO-C 1977. I have a wonderful and supportive partner Andrea with whom I have been in a relationship with for 18 years. We have two lovely children GRO-C and GRO-C

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

Section 2. How Affected

3. I suffer with severe Haemophilia B which was diagnosed at Blackburn Royal Infirmary Hospital when I was aged 6. There was no family history of Haemophilia.

4. I received Factor IX concentrate and I may also have had a blood transfusion before Factor IX was provided but I am unable to recall.

5. Between the ages of 6 to 15, I was treated with Factor IX at Blackburn Royal Infirmary on an intermittent basis, as and when required; depending on how clumsy I had been. On average, I received Factor IX twice per month. This typically meant that I was admitted to hospital for durations of 7 days, however, this largely depended on the severity of my bleed. At the age of approximately 15 I was taught how to treat myself which allowed some flexibility and home treatment was prescribed. I was under the care of Dr Jivani at that time.

6. I attended the Manchester Children's Hospital for yearly check-ups where I was under the care of Dr Stevens and Dr Evans.

7. Currently, I receive Factor IX (Aprolix) which has a longer lasting factor enabling me to take one dose weekly and since 1992 I receive my treatment and care at Manchester Royal Infirmary.

8. I was informed that I was Hepatitis C positive in a careless and flippant manner when I was being transferred from the children's department to adult care at the age of 16. I recall a haematology nurse told me "*You have Hep C, don't you John*" but I had no knowledge of this as I was not told that I had been tested. She jested, checked my notes and confirmed that I was Hepatitis C positive but suggested that I should not worry about it. I was alone during this conversation following which I felt completely dumbstruck.

9. I was provided with no further information and I was left to my own devices. The nurse did not give me any information in relation to my symptoms or risks surrounding Hepatitis C. I researched everything after I returned home.

10. I strongly believe that I should have been provided with adequate information in relation to how to manage and how to treat my infection as soon as a diagnosis was made.

11. The way in which this life-shattering news was conveyed to me was simply unacceptable. The nurse shrugged it off as though I was suffering with a simple cold.

12. When I returned home, I told my mother what had happened and she was very angry as a result. I recall that my mother contacted the doctors following this, but they advised that I should keep taking Factor IX as there was no alternative.

13. I do recall at the age of approximately 13, I became worried about contracting HIV following scares on the television about contaminated blood. I remember that my mother informed the doctor about my worries at an outpatient appointment in Manchester and we were told that I was HIV negative. Moreover, the doctor reassured us that my treatment was heat treated.

14. When I was aged 17, my friend was in a relationship with a girl whose mother was a solicitor. She encouraged me to make a claim against the NHS and considered some of my medical notes. She concluded that I was likely infected at the age of 10. Moreover, the doctors advised her that this information was not disclosed to me earlier because they did not want to disrupt my school life. Additionally, they stated that I should be thankful that I was not infected with HIV, as many others were. It was a '*think yourself lucky*' attitude which was simply not good enough. Unfortunately after several months, the solicitors firm wrote to me to advise that my claim would not be pursued.

15. There was no discussion surrounding any risks associated with taking Factor IX. My mother was a single parent and I was her only child which meant that she was very protective about me. She always told me she was informed that Factor IX was safe to use and that it would allow me to lead a 'normal' life.

Section 3. Other Infections.

16. I do not believe that I was exposed to the risk of any other infections such as vCJD.

Section 4. Consent.

17. I strongly believe that I was tested for Hepatitis C and HIV without my knowledge. For example, during a conversation with my doctor when I was aged 13 after my mother expressed my worries in relation to HIV and the doctor told us straightaway that I was negative. He did not know that I would ask him and I do not recall being specifically told that my blood was tested for HIV so I must have been tested without my knowledge.

Section 5. Impact

18. A significant consequence as a result of my infection is that I unintentionally infected my mother with Hepatitis C following an incident when I was aged 11. At that time we had no idea that I had been infected with Hepatitis C. I was climbing a wall near our house and I fell off injuring my face. My mother was in the kitchen preparing her brilliant stew and my scream of agony made her jump resulting in her accidentally cutting herself. She ran to my aid and my face was covered with blood as a result of the fall. Given that we had no idea that I had any kind of infection my mother didn't take any precautions and helped me exposing her to my blood. It wasn't until 1996, approximately two years after I found out that I had been infected with Hepatitis C, that my mother started suffering with fatigue. She had some doubt in her mind and she decided to be tested and unfortunately she tested positive.

19. Between 1996 and her death in 2016, my mother really disliked going into hospital. When she was transferred to Manchester Royal Hospital she experienced accusations of taking drugs and the doctors did not believe that she contracted the Hepatitis C from me. It was completely unfair. She did not receive any treatment when she started becoming ill in 2016.

20. Her symptoms became very bad in 2016 and on one occasion I went to visit her at home and noticed that her legs were really swollen resulting in her being admitted to Blackburn Royal Infirmary. She had a complication with fluid on her liver. She was coping well, but when the fluid came up to her brain she became very confused. I recall the doctors insinuated that her condition was alcohol-related. Very tragically my mother didn't' make it and she passed away.

21. The loss of my mother has had a huge impact on our lives. My mother doted on our children and her passing has had a miserable effect on our lives. I felt worthless and I blame myself for having infected my mother.

22. When I was 16 and I found out about Hepatitis C I was attending Blackburn College studying Health and Social Care. After approximately 6 months, I ended up dropping out and I believe it was my attitude following the diagnosis. I also refused Factor IX treatment for 18 months because I was petrified about what I might be injecting myself with.

23. Instead I started GRO-C drinking alcohol a lot. GRO-C GRO-C I never injected any drugs. I drank 4-6 pints every night at the weekend. I did not think there was much of a point to make an effort or to live and I was trying to block everything out. I would say that this went on for approximately 4 years until I met my partner Andrea.

24. I think upon reflection I suffered from severe depression. At the time, I did not think about it as depression but looking back it is clear that I was hiding from the reality of my situation.

25. As a direct consequence of my actions my relationship with my mother was not very good at the time. I was rebelling against her in many ways. We used to be so close, but I could tell she was disappointed with me. I did not really care and about anything, I was in self destruct mode.

26. There were days when I felt fatigued but I did not necessarily realise that fatigue was Hepatitis C related.

27. In 2015 I underwent a combined treatment of Interferon and Ribavirin. I felt so much worse after the treatment. It is the worst thing I have ever done and I wish I had never had it. Since this particular treatment, I have not been well and continue to have horrific side effects. I now suffer from so many side effects including, tiredness, skin problems, brain fog, joint pains, fatigue, depression, sweating, weight gain, feeling uncomfortable around my abdomen surrounding the liver area and the feeling of my lungs compressing when I cough.

28. After the treatment, my health deteriorated which resulted in a massive knock on effect on my entire life. At the age of 21, I trained to be a coach and I qualified when I was 25. I have worked with several football clubs over the years, however because my health deteriorated my career has not been as fulfilled as I wish it would have been. I am no longer able to work.

29. Recently, I have been diagnosed with fibromyalgia and I am convinced it is a result of the treatment. During the last couple of weeks, my asthma has worsened and I have noticed that I get out of breath a lot. I have been suffering with palpitations and chest pains. A few tests were carried out but nothing major has been diagnosed apart from angina 6 months ago. I am due to go back for a consultation in May and to do a fitness test and I will be having a blood pressure monitor.

30. Now I have to take each day as it comes. Some days I wake up and have no energy to even move. I have in the past consumed energy drinks in an attempt to give me more energy, but they would only make me feel worse because I then couldn't sleep. I also suffer with long lasting severe headaches and at their worst these can go on for 5 days at a time.

31. I take a 1250mgs daily dosage of citalopram for my depression. I take omeprazole for stomach acid. I take cocodamol as a pain reliever, sometimes

4 times per day and this makes me feel sick. I take gabapentin for my fibromyalgia but this is very restrictive as it makes me drowsy meaning that I have to stay at home. I also take inhalers for my asthma.

32. I just wish that I could turn the clock back to 2015 and I would refuse to take the Interferon and Ribavirin treatment because since I have had it I have become a different person. Essentially, the doctors are monitoring me but not treating the horrific side effects that I am left with after the treatment.

33. If I did not have Andrea and the children, I would have ended my life which is something I have considered many times. I think if I went to support groups, this would be helpful. When I asked for help, the doctors said that there was a support group in Manchester, but a few days prior to the meeting, it was cancelled.

34. My GP, Dr Ahmed does not necessarily want to keep medicating me for my depression and prefers to keep me on a low dosage of citalopram. My GP has offered another antidepressant but I have heard some scary stories about it so I refused. I may need something stronger later as time goes on but for now I am managing.

35. Apart from seeing my GP for regular check ups I attend the Manchester Royal Infirmary. My last visit was in February 2019 under the supervision of Mr Thachell. My visit was mainly based on the haemophilia and joint-related issues. I see a physiotherapist once every 12 months who conducts tests on my joints. I have been recently advised that I ought to be monitored once every 6 months as I have been prescribed the new Factor IX. The doctors advised me that because this treatment is new there need to more detailed notes otherwise they will not get the funding.

36. I keep my infection quiet from my friends. I did not want to publish it as I think there is still an existing stigma. Even when the medical professionals hear about Hepatitis C they automatically associate it with drug and alcohol misuse. My mother was a prime example of this. I live with the thought

everyday that I killed my own mother and I will always blame myself for infecting her with Hepatitis.

37. My mother also kept our infections quiet for many years. I did tell my best friend about it and he never treated me differently. However I will never forget when I was 6 years old and my old teacher told everyone in the school that I was a Haemophiliac. This coincided when the associations with HIV started to be aired on the television and it was at that time that I started to be bullied. I was called the "AIDS boy" by the other school children. I was also unable to play fight with them as they would make comments such as "*you can push us but we can't push you because you have the Christmas disease*". I had a lot of time off school due to bleeds in my joints which sometimes lasted 5 days.

38. My initial fear of being infected with Hepatitis C was the inability to have children. I always wanted to settle down and to have a family and the risks associated with Hepatitis C really scared me.

39. When I met Andrea, I told her about my infection and we discussed the risks of being in a relationship and the risk of trying to have a baby. We both discussed it together and thankfully we did manage to have children successfully. Fortunately both of our children are Hepatitis C clear.

40. Andrea is so wonderful and she is the centre of my world and my rock. It really upsets me that my depression affects our relationship, especially when I unable to go out on days out with the children as a family.

41. We do not go into any detail with our children in relation to my infection. **GRO-C** is older and understands a little more but we feel it is best that we do not discuss it.

42. I have always been really interested in football but given that I am a haemophiliac I have never been able to play. However on a positive note I have managed to work in the area of football. I worked for Rochdale Football Club in 2001 to 2003 where I was the youth coach for the under 18s.

Following that I worked for Bury Football Club as a reserve team manager. Then in 2008, I got my dream job at Blackburn Rovers. I was the manager for the under 23s team and I also helped with the reserve team. I am a Blackburn Rovers supporter. I worked at Rovers until approximately 2011. I then went to Malta in 2012 and worked for Valetta Football Club for approximately 6 months. When I returned to the UK I worked for the Football Association in community coaching.

43. Throughout my time working I would say that I managed my condition pretty well, although I did have rough days I managed to plod along. I was not on antidepressants and I took my Factor IX which was under control. When I returned to the UK, I was experiencing problems with my left hip. Some time ago when I was younger I was diagnosed with Perthes Disease which is a rare childhood condition that affects the hip. It occurs when the blood supply to the rounded head of the femur (thighbone) is temporarily disrupted. I went to see an orthopaedic doctor who was under the impression that the pain I was having was probably from an old untreated bleed in my hip.

44. My job as a coach took its toll on me over the years because it was just so physically demanding. Unfortunately my hip suffered as it was just too much of a strain and I had to have a full hip replacement early 2013.

45. I was able to return to the community coaching in August 2013 until I underwent the treatment of Interferon and Ribavirin in 2015.

46. I did have a previous Interferon treatment when I was approximately 16 years old. It was meant to last for 12 months but at the 3 month check-up the doctors told me that it was unsuccessful. As a result I was unable to continue with it.

47. In 2015, a retiring doctor, Dr Paula Magg-Bolton, suggested to me in a routine appointment that the new treatments for Hepatitis C were a lot more effective than they had been. I was invited to visit the liver clinic to see a presentation in relation to the possible side effects of Interferon and Ribavirin combined

treatment. I was told about the potential for skin problems and the staff stated that everyone was different and each person could respond differently. During the presentation we were provided with case studies of other patients who had been through the treatment.

48. I decided to go ahead with the treatment and I had to inject myself 3 times a week and I took tablets 3 times daily. This treatment made me feel sick constantly and I suffered with severe flu like symptoms. I lost a lot of weight and suffered with severe mood swings. At times I felt like I wanted to put my fist through the television for no reason. My entire family were affected as a result of my mood swings and I frequently locked myself away in my room. Although Andrea really understood and we did not argue about it, I just felt guilty all the time. The treatment continued for approximately 10 months and in early 2016 I was pleased to hear that the virus level was undetected.

49. Following the success of the Interferon and Ribavirin treatment, I was discharged from the liver clinic. Approximately a month after this, the haemophilia clinic tried to refer me back to the liver clinic due to symptoms related to my liver. Unfortunately, as far as the liver clinic practitioners are concerned, I have cleared the virus and they do not want anything to do with me. My symptoms have been worse since the treatment stopped and I feel that I have been left helpless. Although before undergoing the treatment I had bad days, my Hepatitis C was manageable. Whereas since the treatment I feel like my life has been ruined.

50. Before I started the treatment, Andrea worked in a nursing home full-time however it was not sustainable and she had to change to work part-time to keep an eye on me and look after the children. I received disability living allowance and severe disablement payments. However, at the height of my career I was earning approximately £4,500 per month which meant that the £800 which Andrea was earning alone as the sole bread-winner was really difficult to live on.

51. My GP signed me off work and I have been put on the new ESA payments. At one point, the PIP allowance was taken from me. Thankfully, recent legislation changed for haemophiliacs and my PIP payments have now been reinstated.

52. In relation to dental problems, I never had problems until I had the treatment in 2015. I have since had 4 fillings, a root canal and 4 dental abscesses. I attend a dental practice which has dealt with haemophiliacs before.

53. Andrea's parents are aware of everything. I sometimes go out for a drive with her dad and have a chat with him which is nice. We are unable to get a mortgage and we always have to rely on renting as I am unable to get life insurance.

Section 6. Treatment/Care/Support

54. I now find that I am in an impossible situation as now I am officially "*Hepatitis C cleared*" no one wants to help me. I feel like everyone thinks that my symptoms are all made up and that I am imagining them. The liver clinic will not accept a referral for me. I wrote to them directly and I have not had any response from them. My GP advises me that I should be referred via the Haemophilia department.

55. I have not been offered any psychological support or counselling but I would be interested to receive support.

Section 7. Financial Assistance

56. In 2004, I received a Stage One payment of £20,000.00.

57. In 2015 and for 12 months only, I received £135.00 per month from The Caxton Foundation.

58. I receive the Special Category Mechanism payments from the EIBSS of £1,500 per month.

59. In the beginning, I really appreciated the receipt of £20,000 from The Skipton Fund and my monthly instalments from the EIBSS are also appreciated. However, these are only a fraction of what I would be earning if I was able to have a fulfilled career.

60. Unfortunately, we had to get payday loans from companies such as Wonga.com which took a while to pay off. We have had to make major cut backs and we are now lucky enough to be debt free now. We should not have been put in such a stressful financial position.

Section 8. Other Issues

61. I would like for there to be a final solution and I really want the Government to admit liability. I want the victims to be appropriately compensated in a final settlement so that they do not have to feel as though they are begging for support.

62. I follow Factor Eight and Tainted Blood Facebook groups and some of the stories I see which are shared are awful. We did not ask to be put in this position.

63. I think the Government knew a lot more a lot sooner than they let everyone believe. We were cheaper than chimpanzees and I feel that we were used as test dummies. I understand they could argue that Factor VIII and other blood products were the best treatment available at the time but maybe if we were given choice things might have been different.

64. My biggest worry is that when I die my children are looked after financially as I feel that there will not be any protection for them. I feel that this is the least that should be done as if it wasn't for being infected with bad blood than me and my family would never be in this situation.

Anonymity, disclosure and redaction

65. I do not wish to apply to retain my anonymity.

66. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed. GRO-C

Dated 10-5-19.