Witness Name: Stephen George Bartram
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Exhibits:0
Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF STEPHEN GEORGE BARTRAM

I, Stephen George Bartram will say as follows;-

Section 1. Introduction

1. My name is Stephen Bartram. I was born on GRO-C 1971 and I am 47 years old.

2. I am currently residing at GRO-C Norwich, GRO-C I live with my partner, Lisa Nichols and 2 children who are dependant on me. I have 2 other children from a previous relationship and 1 stepdaughter. I am currently working as a self-employed taxi driver.

3. I was infected with the Hepatitis C Virus (HCV) as a result of receiving Factor VIII treatment for my haemophilia.

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

Section 2. How infected

5. When I was 18 months old, I was bitten by a dog, and subsequently taken to the Royal London Hospital in Whitechapel, London. The wound was stitched up and I was sent home. When I got home, the wound would not stop bleeding so my mother took me back to the hospital. Since my grandfather was a haemophilic, my doctor decided to do some tests on me which confirmed that I have mild haemophilia A. This was in or around 1972.

6. I was treated with Cryoprecipitate up until mid 1970s. After this, I was told that the Cryoprecipitate supplies had ran out but that a new drug would be administered called Factor VIII.

7. When my treatment was changed, I was about 7 or 8 years old. I remembered this particular conversation they had and it was out of the norm that my treatment changed.

8. Later, my mother passed away as she was suffering from cancer, and my dad became my main carer.

9. I was administered Factor VIII at the Royal London Hospital up until I left London when I was about 12 years old. During my late 20s, I started administering Factor VIII myself at home.

10. Growing up with haemophilia was not easy. I was constantly in and out of the hospital as I would bruise or cut very easily. I enjoyed many things such as riding my BMX bike, but I had to give this up.

11. When I was still a child in the 1980s, haemophilia was coupled with AIDs and so my friends stopped playing with me. I believe this was because their parents had told them to stay away from me. I was only a child and I did not understand what was happening, but I remember feeling very lonely. I was made to do P.E at school with the girls because I was unable to take part in any contact sport. This made me a target for bullies which affected me a lot. I even had a psychological report done at school due to the bullying I went through.

12. This infection has also had vast educational effects on me. I left school with zero qualifications because of time missed due to my illness and bullying.

13. I was treated for my haemophilia at various hospitals including the following: Royal London Hospital (London), Addenbrooke's Hospital (Cambridge), Queen Elizabeth Hospital King's Lynn, Southend General Hospital, Norfolk and Norwich Hospital. The doctors who treated me at Norfolk and Norwich Hospital were: Dr Julian Turner, Dr Hamish Lyall, Dr Leslie and Dr Black. The doctor who treated me at Royal London Hospital was Dr Brian Colvin.

14. In 1995, I attended a routine appointment with Dr Turner. As I was leaving, she stated the following: "By the way, we found Hepatitis C antibodies in your blood." She stated that they do not know a lot about it but that there was nothing to worry about.

15. We did not discuss this further as Dr Turner did not make it out to be serious. I just thought there was nothing to worry about since Dr Turner seemed so calm about it all. I wasn't told that I was tested for non A/non B hepatitis (now known the HCV). I found this out myself in my medical records.

16. Up until 1995, I always felt fatigued, but I was told that I must be anaemic which is why I am always tired. I never put it down to the HCV as I had never heard of this before. I just knew my health was very unusual, but I did not know why.

17. Following my appointment, I started researching about the HCV myself as I started to get worried about my health. I realised that the infection may be more serious than what I was told.

18. In 1995, I called Dr GRO-D who remembered me as a child when he treated me. During our conversation, I recall Dr GRO-D saying, 'I'm sorry Mr Bartram, it was me who infected you, but I did what we were told to do.' A Few years later when I called him, he denied ever saying that, but I can

confirm that in 1995 he made the direct link between my infection and the Factor VIII treatment.

19. I then booked another appointment at the hospital, which was to be with Dr GRO-D I asked questions in relation to my HCV to which Dr GRO-D did not provide any answers and was being very unhelpful. The answers that I did manage to get were very general and vague, and did not help me at all. I just wanted to know how serious my condition was and what they were doing about it in terms of treatment.

Section 3. Other Infections

20. Due to the second course of medication that I had received for my HCV, I have been suffering from an irregular heartbeat. My heart is only functioning about 85% which is what I have been told by my doctor. I believe this is the direct result of the treatment I received for my HCV as my heart was perfectly fine before that.

21. I was diagnosed with cirrhosis which was confirmed through a fibroscan in around 2016.

Section 4. Consent

22. I believe that I have been tested without my knowledge, without my consent, without being given adequate or full information and for the purposes of research.

23. As mentioned above, I never new that I was being tested until I found out in 1995.

24. I believe I was tested for research purposes as I was never informed why I was having so many tests and blood tests every 6 to 12 months.

25. I was only told that I was being tested to make sure my blood counts were fine after taking the Factor VIII. I did not suspect that the tests were for my liver functions or any other reason and so I did not question why.

Section 5. Impact

26. When I was first told about my HCV, I was very shocked and scared. I was also confused as to why it took the doctors some 11 years to tell me that I had been infected with the HCV. I did not understand what was going on, I thought I was going to die.

27. I started to feel very down and I pushed everyone close to me away and, as a result, I had lots of arguments with my then wife. I felt that nobody understood the infection enough to care; I was very lonely and isolated. I ended up falling in to depression and I even tried to take my own life because I was so down about my diagnosis. I just could not believe I had been infected with the HCV as a result of the Factor VIII treatment I had received for my haemophilia.

28. I had already had 2 children by the time I was diagnosed, and I was terrified that I may have infected my wife and children. GRO-C GRO-C GRO-C This was a very stressful time for me and my wife as we were extremely worried about the children. I felt so guilty thinking I may have infected them.

29. I was surprised that my doctor did not recommend my wife and children to take tests to see if they had been infected. GRO-C GRO-C. GRO-C put a lot of strain on my relationship with my wife. She was so worried about the kids and we were constantly arguing due to my negative attitude and behaviour. As a result, my wife eventually left me because she could no longer cope with the person I had become.

30. This infection has ruined my life and turned it upside down. Had it not been for this infection, my life would have been so different now and I would not have gone through all this pain and suffering.

31. I am constantly fatigued and have been so for most of my life, without ever really knowing why. I have lived a huge part of my life not knowing that I was infected and not knowing why my health was so unusual compared to everyone else.

32. The first treatment that I received for my HCV was a combination of Interferon and Ribavirin in 2007, which was unsuccessful. I was then treated with Sofosbuvir and Ribarvirin in 2016, this successfully cleared me from the HCV.

33. The side effects of the first course of treatment in 2007 were extreme, but it did not stop me taking it. I was merely told this is the only treatment available to me, I felt like I had no choice but to accept this treatment if I was going to fight this infection.

34. When I started my second course of treatment, I was admitted to hospital with breathing problems and I was told I had an irregular heartbeat. I believe the treatment caused this, as my heart was fine before the treatment.

35. I had difficulties in accessing my second treatment, which had to be accepted before a board. Due to the worsened state of my liver, the treatment was granted to me. However, the hospital at first prescribed the wrong drug to me at the cost of £35,000 and I was told to throw them away.

36. The treatments affected me both mentally and physically. Both treatments were horrible and it felt like every good part inside me was being stripped off. I suffered from constant fevers, shivers, sickness, anger as well as depression. I experienced very bad mood swings and sometimes I could barely recognise the person I had become. After everything I had gone through, and then to be told that the treatment had not worked was the worst feeling ever. I had given

up on any hope that I still had to fight my HCV. I was left feeling weak and I was constantly in tears. The worst part is that I had no one to talk to. I wish I was offered some support or counselling to get through this but I was not.

37. I found a career within the catering industry which I very much liked, however, I was bullied out of this job once my manager found out that I was a haemophilic infected with the HCV. This was heart breaking for me as I really enjoyed this job; it was the only thing keeping me going. Every job that I subsequently got in after this, the stigma attached to haemophiliacs and the HCV followed, and so I had to leave each time.

38. My HCV has also impacted my dental care. I have been turned away from dentists once they know about my infection. As a result, my teeth have not been able to receive the proper care and attention they need.

39. The financial effects my infection has had on me is tremendous. During my first course of treatment, I couldn't work and my debts mounted. I went bankrupt, which affected my credit history. My second course of treatment also left me unable to work, and therefore, I was very financially unsecure around that time too.

40. In 1997, I met my current partner, Lisa. We are not married but have been together for about 20 years. She has been very supportive of me, and we have two sons together. However, when we started a family, no advice was given about safe sex. I was constantly worrying about passing my infection to Lisa and my children. I would even be scared to put a plaster on my children if they hurt themselves GRO-C GRO-C

41. I have never known what it is like to live a normal life without being infected. I have been ill all my life; I would love to know what it feels like to be free from any illness.

Section 6. Treatment/Care/Support

42. In 2007, I was offered a course of treatment. I was on the first treatment for 6 months. As mentioned already, this resulted in severe side effects which included: fatigue, shivers, anger, rage and depression. It felt like even the healthy parts in my body were being stripped away. The worst part is that the treatment was unsuccessful. When I was told that the treatment had not worked, I was hysterical because I was sure it had worked. The hospital security even removed me from the hospital because I was so upset.

43. I was told that there was nothing more that could be done for me at Norfolk and Norwich Hospital, and so I was transferred to Addenbrooke's Hospital to be under the care of a Dr Alexander. I had further tests but there was no progress.

44. In 2016 I was offered a further course of treatment. As I have stated above, I suffered from a lot of side effects, the treatment also interfered with my breathing and heartbeat. I spent a lot of time in hospital as a result of my irregular heartbeat, which I attribute to these treatments. This second treatment eventually cleared my HCV.

45. The last time I was tested was December 2018. My results confirmed I was still clear of the HCV.

46. I have never had any proper support from the NHS staff apart from the specialist nurses whilst having treatment.

47. This infection has destroyed my life, but I was never offered any support or counselling, which I would have accepted if offered.

48. In 2016 during the last treatment, I was even misdiagnosed as having HIV which came as a shock to me. I was misdiagnosed in front of my family and a ward full of people. It brought back to me all the trauma of 1995.

Section 7. Financial Assistance

49. I was party to the 1991 group litigation in the USA, where I received £5,000. I had to sign a waiver confirming that I will not make a claim in the USA.

50. I have also received the stage 1 and 2 payments from the Skipton Fund as well as monthly payments of £1500. My first payment was a sum of £20,000 and the second payment was a sum of £50,000. It was a fellow haemophiliac who told me about the Skipton fund.

51. I did have some difficulties applying for financial assistance and I had to appeal once due to some faults on the part of the doctors.

52. I found the process of applying for financial assistance a completely humiliating experience. It was such a long process that caused me so much unnecessary grief.

53. I recall one time I required financial assistance for decoration works that needed to be done on my house. I eventually was offered some money, but I felt like I was begging for this.

Section 8. Other Issues

54. As mentioned above, I was involved in group litigation in the USA where I was made to sign a waiver. I am not a member of any other groups.

Section 9. Anonymity, disclosure and redaction

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

56. I am happy to give oral evidence if necessary.

Statement of Truth

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

Signed….. **GRO-C**

Dated 12-2-19