Witness Name: Charles Gurteen
Statement No: WITN0565001
Exhibits: **WITN0565002 - 03**
Dated: 17 April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CHARLES GURTEEN

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 09 April 2019.

I, Charles Gurteen, will say as follows: -

Section 1. Introduction

1. My name is Charles Gurteen. My date of birth is GRO-C 1972 and I live in GRO-C Suffolk with my wife and two sons aged 14 and 8. I work as the area manager in my long running family business in Menswear fashion.

2. I intend to speak about my infection with Hepatitis C (HCV) from infected blood products used to treat my Haemophilia A. In particular,

the nature of my illness, how the illness affected me, the treatment received and the impact it has had on myself, my wife and our lives together.

3. The Inquiry has informed me of the anonymity process and I elect for my identity to remain public.

4. I confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me with my statement.

Section 2. How Infected

5. I was born with severe Haemophilia A. The condition was discovered when, at the age of 2, I was circumcised and I severely bled both internally and externally.

6. At the time of the procedure my father strapped my arms and legs to the cot to stop me moving and bleeding further. People believed that I had simply been given a bad operation. However, we had a family friend who was a nurse and she suggested I get tested for Haemophilia.

7. I was found to have severe Haemophilia A. I am in the rare position where I have 0.01% naturally occurring Factor VIII (FVIII) clotting protein in my blood.

8. As a young child, from about the age of 4, my Haemophilia was treated with Cryoprecipitate. This treatment had to occur in a hospital and the frozen Cryoprecipitate had to slowly thaw before it was given to me through an intravenous drip, which was a slow process.

9. Using Cryoprecipitate was absolute hell. As a very young child, I remember the large hospital corridors and the nurses with big hats on. It was an arduous treatment regime and there was relatively little FVIII protein in the solution meaning that I had to have it regularly. My father tells me that for 5 years in a row I was in hospital around Christmas time. This was all very disruptive to my early years and my family.

10. Growing up with severe Haemophilia was tough. Due to the bleeds I have fused ankle joints and had to have my knees replaced as it has caused serious arthritis in my joints too.

11. I had to wear callipers on my legs to prevent movement as even the slightest movement would cause me to bleed. Often with no movement at all I would still bleed. Thankfully my family is in the clothing industry and so trousers were made specially so that I could wear them over my callipers. I have very little muscle on my legs to this day because of being immobilised as a child. We would try and develop my muscles but this would often cause further bleeding.

12. Cryoprecipitate did not work that well because the level of clotting factor in each batch was poor. My understanding was this contained about 50 units of factor per batch. My doctor, Dr Chalmers, at Old Addenbrooke's encouraged me to use the heat-treated factor products in the 1970s. Unfortunately, he died of cancer, and I was then under the care of Dr Seaman.

13. I am now under the care of specialised nurse Emma Warner for Haematology. I have been treated throughout my life at both Old Addenbrooke's and New Addenbrooke's Hospital in their Haematology Department.

14. By 1977, I was being treated with FVIII concentrate from the Bio Products Laboratory (BPL). Factor VIII concentrate was lifechanging and made me feel less abnormal as I did when going through treatment

using Cryoprecipitate. These new products carried around 3000 units of factor per batch. The dosage is calculated by your weight.

15. Due to taking part in Hepatitis C litigation, (August 2004) I was able to secure information from the United Kingdom Haemophilia Centre Doctors' Organisation (UKHCDO) about what products I have been treated with throughout my life. Dr Baglin was informed via a letter **Exhibit WITN0565002** from the UKHCDO with information from the National Haemophilia Database. I did return several documents to them (Lieff, Cabrasher, Heimann & Bernstein) regarding my treatment. The time frame they set for me to return the documents was unrealistic, suffice to say, the litigation did not go anywhere.

16. I therefore have a list **Exhibit WITN0565003** of what products I was taking between 1977-2002 (which was up to date at the time). It details what Haemophilia Centre I am treated at as well at the material type and description. I have been treated with a number of similar products including: Armour FVIII (Factorate), PFC FVIII, Cutter FVIII (Koate), Oxford FVIII, BPL FVIII 8Y, BPL Opivate and as of recently I am on a trial of a product called Elocta.

17. The treatment I am currently on is called Elocta. This is a slow releasing FVIII. Whereas traditionally the product would give you the clotting factor all at once which would then decrease quickly in your blood requiring another dose, this is constant and is a slow release allowing for the Factor levels to remain high for longer. Mine is self-administered through a needle of 4500 units once every 5 days. This was actually a clinical trial where the product was yet to be licenced in the UK. The results were being fed back to the US throughout. This was a successful trial and is now being used by other Haemophiliacs.

18. I have always been a keen supporter of the Haemophilia Society and the NHS and I like to help wherever I can. I am not one to sit back and

wait for the science to advance, I want to be a part of it. I have therefore participated in a number of trials; the Opivate treatment was also a trial.

19. I have been told that I was the first child to be given FVIII administered at home. The introduction of FVIII products was such a positive change in the treatment of Haemophiliacs. It was bliss. It was lovely to see a bottle of the product with a syringe and needle all together. It allowed for self-administration in the comfort of your own home or School. I only had to inject every 3 days.

20. Although I do volunteer to take part in these trials, I have always felt like a 'hamster' As one of the first children on FVIII I was testing it in hospitals before it was offered at home so I was a trial patient of sorts then too.

21. Recently, I spent a number of months preparing to take part in a trial for gene therapy. If gene therapy is successful Haemophiliacs would not have to take any injections as the faulty gene would be replaced and I would make enough Factor myself. I would be just like you.

22. I spent 6 months preparing to be one of the 12 people on the trial. My body had to be clean and so I was not to drink any alcohol. When we were just about to start it they said I was unable to do so because they had detected a disease in one of my blood tests. Therefore, I cannot take the gene therapy because it won't work on me. I have no idea what this disease was or whether it related to the Hepatitis C infection I had.

23. That really broke my heart and I just burst into tears. I should have been told that a lot earlier if I was not suitable.

24. As a severe Haemophiliac, my school life was particularly tough and I missed a lot of time due to being in hospital. I remember at my prep

school, Barnardiston Hall School, the class would draw me little pictures and get well soon cards. I remember those things and still see those friends today. I went on to King's College, Cambridge when I was 10 years old and this is where I learnt to inject myself because the matron would kill my veins otherwise!

25. I took my Common Entrance exams and hoped to secure a place at the Leys in Cambridge. I had dreamed of going there as they were a sporty school who were known for their swimming. This was a sport I could participate in and I really enjoyed it. It was so good for my muscles and bones; I even swam for East Anglia. Unfortunately, the school didn't let me in due to my Haemophilia and this broke my heart. So, I attended the nearby Stoke College instead.

26. As I got older school got harder as the boys would be running around playing football and I would be alone. I couldn't play rugby or squash as I would just end up in the sick bay for a week afterwards with a bleed. This time was tough as I also had epilepsy due to a brain tumour and I was bullied and teased for it. My A-Level results were not fantastic as I had missed out on so much education.

27. I am unsure of the dates during which I was given infected blood products. It could have been at any time from the age of 5, (1977) when I was put on the factor VIIII blood products. **See Exhibit WITN0565003.**

28. My parents have told me that they categorically were not told about there being any risk of contamination of the FVIII blood products and therefore were not warned of any potential infection to myself.

29. I went for a liver biopsy for the first time in the early 1990s. I had no idea what it was for. I thought 'why do they want these samples?' At the time no one knew what Hepatitis was so I do not remember thinking it was anything related to that.

30. Liver biopsies are excruciating. You cannot be put under a general anaesthetic. You are given 3 local anaesthetic injections; 2 shallow injections and 1 deep one. A large elasticated needle then springs into your liver and out again with a segment to test. You could not move at all throughout and sometimes they would get it wrong and would have to repeat it.

31. When I was still young, perhaps 10/11 years old, my parents received a letter informing them that I had Hepatitis. I am not sure of the contents of this letter exactly, but I believe the letter came from Dr Baglin. I can only assume that this was as a result of the blood tests I had had as a matter of course.

32. As there was little known about Hepatitis in those days, they had yet to identify HCV as a strain of Hepatitis and still referred to it as NANB Hepatitis, my parents decided not to inform me of the infection. There was certainly no cure for it at the time, and I imagine that due to the lack of knowledge surrounding the infection my parents (and doctors) would have been unaware of its impact as an infection.

33. Sometime in 2002, when I was about 30 years old I went to one of my regular appointments at Addenbrooke's with my girlfriend at the time, my now wife, Jo. I would usually be seen by a Consultant Haematologist or a specialist. Often, they would ask if I minded them having a trainee/student doctor to assist. This particular instance however, we were seen by a student/trainee doctor alone without the specialist present.

34. She was an embarrassment to myself and my wife. She informed me that I had Hepatitis C and it was like listening to a cassette machine. She said 'do you realise you have Hepatitis C' and then went on to robotically explain the life of the HCV infection and how we weren't to share towels, toothpaste or toothbrushes due to cross contamination.

35. I believe she then handed us some leaflets or paperwork that explained what was right and wrong related to the infection and its management. This included information about not having any unprotected sex or intimate relations. This was hard to hear. I had been with Jo for around 4 years at the time and it was hard for her to think I had not been up front and honest with her. I had been as honest as I could possibly have been, she knew about the severity of my Haemophilia but I could not tell her about the HCV as even I did not know. She was very disappointed and it was hard for us. Fortunately she is a very caring person and we stayed together.

36. That trainee told me in such a way that you could tell she had repeated the same lines to many others and then we were just left to walk out of the door in tears. Nowadays I would certainly have put a complaint into the NHS about this particular woman.

37. The Hepatitis C infection came as a total shock. It was so unexpected. Everything surrounding this infection felt very hidden and unknown. I would be told to have liver biopsies without really being told why they were needed for example.

38. I do question why I was not told earlier that I was infected with Hepatitis C. As a Haemophiliac I was having regular blood tests. Why wasn't this identified earlier?

Section 3. Other Infections

39. I was not infected with anything other than Hepatitis C from the use of infected blood products.

40. However, in 2001, I was sent a very scary letter with a standard apology in that it mentioned the need to notify me that a batch of FVIII that had been contaminated with vCJD and that I needed to go and have a test. My heart sank and I thought 'here we go, not again', but I was luckily not infected. I do not see why we needed this letter sent to us in this way?

41. I have also been tested for HIV and thankfully remain negative.

Section 4. Consent

42. I do not feel that I have been treated or tested without mine or my parents' consent, knowledge or full understanding.

43. I have been treated in a number of clinical trials related to Haemophilia. These were not research tasks carried out without my consent. I believe I have always been given adequate and full information surrounding these circumstances.

Section 5. Impact

44. Mentally, finding out that I was infected with HCV was really tough. I found out with my now wife and it was totally unexpected; a complete shock. I think I had to hold it in at the time as Jo was crying. She was very disappointed and upset, it was very hard.

45. The mental impact made our relationship difficult for a while. We had a few months of uncertainty on how to go about our relationship.

46. Every 6 months I was to have an appointment with a Hepatitis Specialist at Addenbrooke's. I told them that I did not want to see the

junior Doctor who told me of the infection so insensitively again and that I wanted to see the original specialist.

47. When I went to my appointment 6 months later, my consultant managed to calm things down. I think the same situation had happened with other people. I believe that female junior doctor did a lot of hurting people's hearts. I do not know her name.

48. My consultant explained that my HCV level was actually stable and had not been getting any worse. He was very good and he calmed us by explaining that, his manner was very professional.

49. Physically, it is easier in hindsight to notice what I was feeling during my infection. I had been left untreated for years. From 2002 onwards it was about 6 or 7 years from when I was informed of the infection to when I was treated. It is likely that I was infected when I was very young. The infection was not identified as Hepatitis C for many years. That said, my parents were informed by letter that I had Hepatitis when I was still too young to understand. Unfortunately that letter and many others were lost in a house fire several years ago.

50. I was really tired and lethargic. I also felt that I had a lot of anger. My concentration levels were poor and it has never really materialised since. Such issues were visible throughout school. I am not sure if the Haemophilia gave me the tiredness or whether it was underlying HCV. I also felt a brain fog. There were many times where I can't remember anything I listened to during a car ride for example, and my concentration was poor.

51. Due to the severe bleeds my joints felt all the effects. I have fused ankles and I have had to have replacement knees. I also have chronic arthritis and have to take medication for this as well as for my blood disorders.

52. When I was 7 years old I got epilepsy, Petit Mals Seizures, and had to go onto anti-epileptic medication as well. I had an MRI and they found that I had a brain tumour. Due to my age the decision was made not to inform me of this. After a year the scan was repeated and showed that there had been growth and at the age of 20 I then had this removed in brain surgery and the epilepsy stopped. I am still on medication for this

53. This tumour was on the memory section of my brain and it was a whopping great tumour! This could therefore be a reason why I have poor memory.

54. When I had my brain tumour removed I caught Meningitis from contaminated instruments. I had recovered very quickly from the tumour and had the necessary speech therapy but I couldn't take the fluorescent lights on the ward. I would scream and shout and these were obvious signs of Bacterial Meningitis. If I had been what I describe as a normal patient I would have sued the NHS. I wasn't a normal patient; I am a severe haemophiliac who needs the on going medical help of the NHS.

55. The use of contaminated instruments is worrying as I had Hepatitis C at the time. Were the instruments used on me sterilised properly thereafter?

56. 10 years ago, they found another tumour in my head. I had what was known as 'dagger knife' surgery where my head was screwed in place and a laser system zapped through the tumour. They are not sure what caused my tumours but I am sure this was something to do with the infection or Haemophilia medication.

57. I also have an issue with my pituitary gland tumour, which is still on going.

58. Being a Haemophiliac with epilepsy, multiple brain tumours and Hepatitis C, I was exhausted. I should have been in my prime but I had such severe fatigue and anger. The fits were triggered when I was tired and so the Hepatitis related lethargy affected me severely.

59. In 2008/9 I was given treatment for my HCV infection. Before this point there was no solution, I simply continued to have check-ups and numerous liver biopsies; I believe I had 4 or 5 in total. I was told that there is this cure and I had heard about the side effects for quite some time. In the long term it was decided by my wife and I that I should go through it.

60. I was treated with Interferon which I self administered as an injection taken in the stomach once a week. I also had to take 2 small tablets every day. This course of my treatment lasted 6 months and I started in the May, just after my birthday.

61. To begin with the dosage of Interferon was wrong and I was being given too high a dose, but then they reduced my levels to a suitable amount. I had appointments throughout the 6 months where such issues would be monitored.

62. I always took this injection on the Friday evening. It made me extremely aggressive and I never ate. You could not drink alcohol for 6 months. The injections made me feel like I either wanted to sleep or die, and so I would be in bed for the whole of Saturday.

63. I had to take it on the Friday to manage being at work on the following Monday. It was awful come Monday. It felt like being in Alcatraz, my parents have always said that I have always been a happy person. I was always helping people but overall it was hell for those months. My personality drastically changed. My wife says I was horrible to live with.

64. Whilst on the treatment I felt zombified. I had a few bad patches on my skin occasionally but they were nothing to worry about. The specialists were notified when I found some and said it was a side effect of the Interferon. The patches spread around but diluted after a week or so and looked like a rash. Throughout the whole 6 months, more or less, I felt itchiness. It was like having an allergy and I felt it on the inside of my legs.

65. I felt so sorry for my wife because I was aggressive; I wasn't a nice person but luckily, she is a very caring and loving person who could just about cope with me. We were warned about this so my behaviour was not unexpected. I lost about 5 stone in weight during the treatment so that might be a positive!

66. At the end of the 6 months I was tested again, by blood rather than a biopsy this time, and I was notified that I was clear of my Hepatitis. I was told this face-to-face but also in writing. I feel very lucky that this treatment worked for me.

67. I now have check-ups every 3 months where my blood is taken and lots of different things are tested. When my blood is taken they usually take about 20 vials.

68. It is hard to know what further complications have been caused by the infection, the medication or any of my other medical issues. I am still angry but not as bad as I was. I had a lack of patience which could have been due to the tiredness. Additionally, however, such issues could be due to the tumour on my pituitary gland so I tend to blame my anger on that. The tiredness could have been caused by any number of things, but it certainly improved after being cleared of the infection. The Interferon made my joints extremely painful, however the severity of my Haemophilia means that my bleeds do a similar thing.

69. The only obstacles I faced in accessing treatment was the fact that there was no HCV medication or cure available for years after my initial diagnosis of Hepatitis.

70. With regards to any other treatment I have needed I do not feel that I was treated differently to other patients due to my infection, although I did always have to declare my infected status. When I declared this to my dentists there was no particular reaction. They were very professional and always wore gloves anyway; instruments were thrown away after their use. I felt no differentiation for treatment times and I wasn't treated like someone unordinary.

71. My family, private and social life were not impacted tremendously however this is largely because I kept my infection status very private. I know that there was a huge stigma around HCV as well as HIV/AIDS and so I did keep as much as possible to be private. I only ever felt any stigma, judgement or mistreatment from that trainee doctor who informed me of my HCV infection. She was the only person I remember keeping me at arms' length.

72. The lack of knowledge around the infection meant that it didn't really mean anything to anyone. I was relatively young and so I think I took it all with a pinch of salt due to naivety. It hit home a lot more with age when the provenance of the blood supply was nationally known to come from American drug users who were donating blood.

73. For my family, my two elder siblings were away, one as a Gurkha Army Officer and one was living in London. However, my parents had to feel the full effects of both my Haemophilia and my infection, as did my wife. I feel sorry for them and I carry a lot of guilt with me for how I caused their lives to be.

74. My wife is very understanding and caring, but there was a while at the beginning when the infection nearly broke us up. It must have been

hard for her at first when it was scary and unknown and then again when I was being treated and experienced horrific side effects. We now have 2 healthy boys aged 14 and 8.

75. A lot of my educational limitations and disruption was due to my Haemophilia rather than my infection. However, my working life has certainly been impacted. I will go into more detail later in my statement.

76. After school my father would not let me join the family business straight away. I went to Cambridge Arts College and studied textiles, business law for 2 years. This was a great time of my life as I lived in the city and felt some real independence.

77. From there I had a year off and went to help mentally handicapped children in a valley in Wales. I was getting swollen and sore joints during this and the company began to manipulate me. They would start picking up on tiny things I was doing wrong so that they could get rid of me, which they eventually did, I wasn't in it for the money so this was very upsetting.

78. After a few months, around the age of 21, I was allowed to begin at the family business. I was on the production and manufacturing side. We would complete 10,000 trousers a week and it was a great feeling on a Friday when we could say we had hit out targets.

79. As the manufacturing side of the business died I moved into the sales side. I had wanted to do this as this is what my father did. This role involves travelling to various exhibitions and trade shows and having a stand there. It used to be held in Earl's Court, and then the NEC in Birmingham and has recently changed venue again.

80. I have felt the effect of the Hepatitis infection and the Haemophilia in a professional capacity. I am the first 'Gurteen' in all the generations not

to be a Managing Director of the company. I had to disclose my infection to the other members of the board and they felt that I spent too much time away in hospital and missing out on important aspects of the business. This really hurt both my wife and me emotionally but also means that my family and I have lost out financially.

81. I think one finds in my situation, when you are born with severe Haemophilia, that you take life it as it comes. It is never ending and so I am very pragmatic in my approach to my life.

Section 6. Treatment/Care/Support

82. I was never offered any form of psychological support throughout my life as a Haemophiliac and as someone infected with HCV as a result of contaminated blood products.

83. There has been a lack of support and had I been offered any counselling at the time I would have taken it.

84. Now I am through the worst of the worst and I have been clear for 10 years. Other than my pituitary gland issues, life is good now so I don't feel the need for any psychological support.

85. I am aware of the support being offered by the Inquiry through the British Red Cross.

Section 7. Financial Assistance

86. I found out about the Skipton Fund at the same time as many other Haemophiliacs infected with HCV did as it became nationalised. We all

went to regional meetings to hear more about it. I was sent lots of paper work rather than being notified of anything in person.

87. I filled out the forms and took advice and support from the Haematology Department at Addenbrooke's. I found it a straight forward process on the whole.

88. I received the Stage One payment of just under £20,000 and I now receive £1,485 per month from EIBSS which has replaced the Skipton Fund.

89. Additionally, I have been sent information about the Caxton Fund. I am eligible to apply for funding should I need to as I have received a Stage One Skipton Payment.

Section 8. Other Issues

90. I am sure all of what happened with Hepatitis and HIV was known well before it was nationalised. It was known about a lot earlier. I feel that they should be seriously fined for what has happened; the people who were guilty for the contamination whether that is the pharmaceutical companies, the government, or someone else. I want the guilty people to pay the consequences. Someone somewhere made catastrophic decisions, which has destroyed people's lives.

91. Who knew? When did they know? Why did they allow it and how did they allow it to happen? I do not feel that the people responsible for this will ever have to face the consequences. I hope the Inquiry identifies answers to these questions.

92. I would also like to add, my Hepatitis C infection has impacted on my wife and her wish to donate blood. Even though I am now clear and

she has never been infected, she has been advised to stop which has upset her.

93. I have been asked if I have ever had to sign any form of disclaimer regarding my Hepatitis. My answer to that is yes, a long time ago when I was about 15, I cannot remember the full details but I think it was to do with not taking any action against the NHS. Dr Baglin at Addenbrookes was involved. That's all I can remember.

Statement of Truth

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

Signed GRO-C

Dated 17th April 2019