Witness Name: Derek James Douglas Wherry
Statement No: WITN0097001
Dated: 3 July 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DEREK JAMES DOUGLAS WHERRY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 April 2019.

I, Derek James Douglas Wherry, will say as follows: -

Section 1. Introduction

1. My name is Derek James Douglas Wherry. My date of birth is GRO-C 1975 and my address is GRO-C

2. I am a severe haemophiliac who was infected with Hepatitis C (HCV). I have one son who is 19 and two stepdaughters who are 28 and 30 respectively. Up until six months ago my son lived with me but has since moved to live with his mother in order to be closer to his job.

3. I am divorced from my wife who GRO-C. My mother and sister both live in Guernsey where I was born and lived until I was 11 years old before I attended Treloar School and College in Hampshire.

4. I intend to speak about my infection of hepatitis c which I lived with for 25 years. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me and my family, and our lives together.

5. 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

6. I was born in Guernsey and lived there until I was 11 years old. My mother bought my sister and I up by herself as her and my father split up when I was young although I believe I am the product of an earlier reconciliation between them. My mother worked as a secretary/ PA and my father was initially a navigation engineer for the RAF before he came back to Guernsey and became an accountant. My sister works as an accountant now.

7. I was diagnosed with severe haemophilia at three months old. As a baby I was constantly covered in bruises which led to me being tested. I believe my mother experienced a lot of stigma in the 1970s for having a baby who was constantly bruised. Lots of other parents gossiped when she took me out and about and people always questioned what she was doing to me and how I was being treated. Once I was diagnosed everything made sense.

8. As far as I am aware, there is little history of haemophilia in the family except for my grandmother's brother, Keith, who was a haemophiliac and died when he was 11. This has been a massive shame to my family because at the time of his death no one ever spoke about haemophilia. These days hiding haemophilia seems crazy to me but

back then it was a different mentality. My mother and sister are GRO-C

9. As a child I spent most of my childhood covered in bruises.

10. I attended St Martin's Primary School in Guernsey and whenever I was bullied there the head teacher, who was a lovely man with a brilliant heart, would deal with it by dragging whoever had done it out in front of the whole school to show what had been done to me. I understand what he was trying to do but I hated it because he highlighted how weak and pathetic I was.

11. Everyone just wanted to punch and bruise me so my social life at primary school was very difficult. Looking back I don't know how my mother coped with the stress of bringing me up.

12. I had a lot of trouble with my ankles, my right ankle was a 'target joint' and I would often have severe bleeds into the joint so it became inflamed. As a result I spent a lot of time in a wheelchair throughout my childhood and my skeleton wasn't able to develop properly. This has meant that I am religious with exercise now and try to walk my dog on a five and a half mile route everyday.

13. When I had a bleed I was administered cryoprecipitate ("**cryo**") at the hospital. Once I turned 7 I was allowed to put the needle in myself, which I preferred, and the nurses administered the cryo to me. I was treated with cyro for most of the time I spent in Guernsey before attending Treloar School ("**Treloar's**").

14. I cannot remember the exact date but I believe I received some early Factor VIII ("**FVIII**") in Guernsey for a short period of time before Treloar's. It was different to cyro which was always a long and boring procedure, I went from being administered a bag to a 100ml syringe

which was a big difference. In Guernsey the blood products were sourced from France.

15. Between my mother and the states of Guernsey, they believed that growing up and attending the state schools in Guernsey wasn't the best way to go, given the ignorance towards haemophilia. It was agreed that I was to attend Treloar School and College from the age of 11 onwards.

16. I wanted to stay in Guernsey and go to secondary school there with people I knew. I voiced my opinion but wasn't heard.

17. Looking back, at that time I didn't want to go, however on reflection I now understand what my mothers thinking was at the time, she was scared and made this decision in my best interests.

18. In September 1986 I moved to Treloar's aged 11. I felt abandoned and betrayed after my mother left. It was horrible and I wasn't able to bond with anyone at first. I never really made close friends there. I was the only haemophiliac in my dormitory; the other boys had spina bifida, cerebral palsy and similar disabilities. I had never known or lived with people with such severe disabilities in my life and I felt like an absolute alien. I couldn't understand why I was there.

19. Treloar's was sold to my mother and I on the promise of camaraderie and targeted physiotherapy for haemophiliacs. I believe if you asked anyone who went there they would say they got sold a dream. I was told that I could do physical activity at Treloar's but once I got there we weren't allowed to play football or do anything. We were outsiders in the disabled community that attended Treloar's, all the haemophiliacs were fundamentally able-bodied compared to the other students.

20. I don't think Treloar's knew what they were dealing with when it came to the haemophiliacs, we always played up and got in to trouble.

21. I was constantly in trouble at Treloar's, I did everything I could to muck around and didn't really pay attention in class. I started smoking when I was 12 and we would steal alcohol after important meetings with the Governors. I eventually managed to make some good bonds with the other haemophiliacs at the school but because of my behaviour I was asked to leave aged 17. I got a few good GCSE grades but overall I didn't do very well. I never took my secondary school education seriously because I felt like I had been left a Treloar's and shouldn't have been there. I was wild and didn't respond well to authority, when they tried to control me it made me rebel even more.

22. I had a few serious bleeds whilst I was there, usually in my right ankle which was a massive weak point for me. Immobilisation was policed and I was carefully monitored, it seemed to me that whenever I had a bleed everyone around me knew.

23. The haemophilia centre was located in the upper school so when I was in the lower school and had a bleed I had to be taken by mini bus to the centre to be seen by a doctor.

24. Jane Yeomans (nee Curshaw) was the nurse who administered the FVIII to the students. She was an amazing woman and I still see her now. I think once I had a bleed quite close to my kidneys and they treated me like I was dying. I was in the sick bay for what seemed a week. I couldn't understand why.

25. I think at the time, the haemophilia specialists at Treloar's haemophilia centre were committed individuals who were operating at the top of their profession.

26. Dr Minear Wasef was an Egyptian doctor and a good guy, Dr Ashok Roy was another doctor but no one liked him, he fell out with everyone

and had no beside manner. Dr Aronstan was the overseeing lead doctor but we never saw him much.

27. I never felt like I saw anyone being used as a guinea pig but we were young at the time. I had some strange tests including psychological ones. I was never sure what they were about.

28. I had blood tests all the time, they were periodioc and I think about once every six months we had a full blood test. I understand that one was to test the FVIII efficiency. They always seemed to be taking blood and the tests were quite basic at the time. I never knew why or what for.

29. I will never forget the day I was told that I had hepatitis. I think it was coming up to my 15 or 16th birthday. It was a very surreal experience. I was called into the office by Dr Wasef and Dr Roy from the haemophilia centre.

30. I was sat down on the examination couch and told in a very matter of fact way that I had been infected with hepatitis. I think it was something along the lines of "you have been infected with non-a non-b".

31. They were very cagey about what it was, there was no alluding to the long-term prognosis but I know that I was already aware of that at the time. No counselling or psychological help was offered to me, it was all very matter of fact. I was told I was infected and had liver damage and it was left at that.

32. I remember I left the appointment and didn't go back to any of my classes that afternoon, I sat on the swings and one of the other students, Christopher Piggot was sent to come and find me. I later found out that he had been infected with HIV and he was actually one of the first to die. He had Von Willebrand Disease and had always been

more able bodied than me and he died before his 20th birthday. We couldn't understand what had been done to us and why.

33. I realised how absolutely alone I was, I didn't feel part of anything else. I thought at the time that I would never be able to have children. I had been warned about risks of transmission when I was diagnosed and that was about it.

34. Because of the way I had been told and due to the lack of counselling from Treloar's I developed my own coping strategies and defence mechanisms to help me process and cope.

35. I am not aware of any haemophiliacs succumbing to the effects of the viruses whilst I was still at school. I think the first death I became aware of was when the guy was around 19. Some of the other students with muscular dystrophy sometimes died at school and it was awful, it made us realise how fragile life is. I found I coped by distancing myself.

36. Before I left Treloar's I attended Alton College on day release. But I was living with the knowledge that I had non-a non-b hepatitis at the time and I stuck it out for about six months before leaving. At some point over the next few years 'non-a non-b hepatitis' became hepatitis c, it just became common knowledge and I was never officially told.

37. I was at Treloar School from ages 11 – 17. I never felt like I belonged there, I was always a square peg in a round hole and they wanted me out before I went. I did used to get on very well with the headmaster's secretary. I think she could tell that the haemophiliacs did not fit in there, she understood me. Her name is Helen Burton, she was very much a people person.

Section 3. Other Infections

38. I was tested constantly for HIV but it was always negative. I have been informed by letter, that I have received blood product, which was infected with vCJD. That was again so matter of fact, no follow up, it was more like a disclaimer notice, a mail shot.

Section 4. Consent

39. Treloar's was always a loco-parentis arrangement; I was constantly having blood tests whilst at school and assume these all fell within the arrangement.

40. I have never formally been offered the opportunity to provide my consent but as far as I know the blood that has been taken and tested since I turned 18 has been to monitor my liver function and haemophilia.

41. I have never consented to the results of my blood tests or HIV status being published anywhere or given to anyone but me but that has happened in the past which I was discuss later in my statement.

42. I do not wish for my results to be used for any form of research or further testing, the government has already inflicted enough on me without furthering my discomfort.

Section 5. Impact

43. After I left school I found it difficult to get into work, I went back to Guernsey but found myself in limbo as my new English friends were in England still and my old Guernsey friends had moved on with their lives. I moved back in with my mum but we fell out and I moved in with gran. I was quite horrible to my mum, I felt absolutely betrayed and wasn't easy to live with.

44. I had a massive chip on my shoulder; I thought I had been given a really bad deal and that I would die young. I struggled with the stigma and what society thought of me, I was a haemophiliac and a virus carrier. Because of that I didn't get into relationships very easily. I didn't really feel human so it was very difficult. I felt like a pariah.

45. I have experienced a lot of negativity from other people throughout the years, specifically from one ex partner. I've had to work hard at not having a chip on my shoulder since I was diagnosed with HCV.

46. I dabbled in lots of different types of work but my first proper job was in IT, as a data processor and then as a photocopier and fax machine engineer. After school I could never understand the importance of holding a job down.

47. There was one job I really wanted which was to work for Midland Bank but by the time I was offered it I had already decided to move to Cornwall. I turned my back on a decent job and I sometimes wonder what life would have been like because getting into the finance industry in Guernsey could have been me sorted.

48. I moved to Camborne in Cornwall with a girl I knew from school. We then moved to Bedfordshire and then on to Surrey where we eventually split up when I was 21/22. I didn't work and I signed on to benefits during the time I was with her.

49. After we split I worked in Redhill as a Customer Service Adviser for Lombard Motor Finance. GRO-C GRO-C During this time I met a girl who would go on to become my wife. GRO-C GRO-C GRO-C, I

also found out that I was going to be a dad and was involved a car accident. It was not a good time in my life.

50. GRO-C GRO-C. At this point I lived in Bordon and worked for the British Car Auctions.

51. GRO-C GRO-C. A journalist who was present wrote an article about my case. He printed my name in the local paper to where I lived, which included my Hepatitis C infection and my negative HIV status. He also printed the location I worked at.

52. The paper was called the Surrey Advertiser. He published the fact that GRO-C and I lost my job with the car auction. I understand he had his job to do GRO-C. He didn't have the authority to speak about my HCV infection and my negative HIV status.

53. Whilst I lived in Bordon I went to the local dentist surgery but was told I had to wait until the end of the day to be seen, that made me feel subhuman and I never went back there after that. This also happened with a dentist I visited in Brockham, Surrey.

54. GRO-C I decided to start learning about the law so for the next three years, during which my son was born in 1999, I was basically a student. I was studying for what I thought was going to be my future career. Eventually I gave this up and GRO-C GRO-C This made me feel like I was getting one up on the government after all they had done to me. I was very angry.

55. In the early 2000s I moved to Alton, my son's mother and I were having some struggles in our relationship so we decided to get married for stability. Our relationship lasted 7 years in total during which time she

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GRO-C it's impossible to say.

56. My son has never been tested, I researched linear transmission of Hepatitis C and when the male parent is infected the likelihood of transmission to the son in phenomenally low. I regularly ask him now if he wants to be tested but it is his choice not mine.

57. Trying to live through the stigma and maintain a positive image for myself was very difficult. I wonder if sometimes I used the virus as an excuse and blamed a little too much on it. I sometimes look back on my life and question the decisions I have made. It is only recently that I have managed to get stability.

58. Hepatitis C defined me for 25 years of my life. I have always felt completely ostracised from society because of it. I have always felt so alone. I find that it is too much for me to have the emotive conversations with the other haemophiliacs I know that are still alive today. I have found that since the Inquiry started I have actively avoided conversations that might drift towards 'danger' subjects.

59. These days I am purposely not negative or anti-social and I do my best to embrace social opportunities. Throughout my life I have missed a lot of opportunities with friends and women and I have had to change that.

60. Trying to explain my situation to someone who is younger than the contaminated blood scandal is like speaking a different language; even if they are also suffer from haemophilia. The justification I would have used years ago has no substance anymore; I am almost stuck in limbo.

61. I have had to watch my friends die for absolutely no reason and the inability of the government to address the issue has contributed to a lot of anger. I used to live with a massive amount of guilt, I didn't understand why I was ok and my friends were dying, then I was told I

have cirrhosis of the liver and realised that I am in the same boat. I've had to take charge of my own mental health and wellbeing because I have never been offered counselling or help.

62. I am so angry about what's happened to me. The stigma towards HIV/ Hepatitis C sufferers has been shocking and always contributed to my anger. Haemophiliacs and intravenous drug users have always been lumped together.

63. I actually know intravenous drug users and they used to explain their needle marks in their arms away by saying they were haemophiliacs. I remember the 'Don't Die of Ignorance' campaign, to me it's another example of haemophiliacs being lumped into those groups by society.

64. Haemophiliacs never put themselves in this position voluntarily; drug users have always done it to themselves. I have been tarred with the same brush my whole life; the ignorance of my peers has shaped my entire life.

65. My mother has GRO-C and still lives in Guernsey. I think she lives with a certain amount of guilt that she just cannot deal with. I can't broach the subject with her at the moment as she is GRO-C and we use a tablet to communicate. If I had the opportunity I would like to reassure her that I do not in any way hold her accountable for what's happened to me.

66. My son knows everything that I have been through and I think over the years it has affected him quite badly. When I went through my second round of treatment he was older and more aware. I have asked him constantly since he was 14/15 if he wants to get tested. And I have always known that if the results came back positive whilst he was still at school it would have drastically changed his school life like it did mine.

67. My older sister has been affected in a number of ways. She is a GRO-C so didn't have children until she was much older as she saw what my life was like. She GRO-C and was screened and found out early in her pregnancy that her daughter GRO-C GRO-C I think my sister looks at me as quite a strong individual who is someone to aspire to.

68. My niece asks about my scars on my arms, she is a very bright girl and you have to explain things to a child, if I don't answer her she'll drag it out of me.

69. My mind set has got me through this experience. 10 years ago I was a completely different person but now I have been through the most horrendous experience with the treatment drugs and I am still alive, they didn't kill me.

70. Being a haemophiliac, my entire life I have basically always been recovering from something, and this recovery mind set has become very empowering. Having gone through the effects of the treatment and the chemical poisoning and having to administer that to myself, knowing that I had no choice but to do it, to have got through all that and come out the other side is a very empowering feeling.

71. These days my haemophilia is under control, I take no medicine for it but have FVIII in the fridge at home in case I have a bleed. GRO-C GRO-C I don't know how I am so able bodied compared to other haemophiliacs my age.

72. I have always had a bull in a china shop approach and have ignored the wishes of medical professionals over the years. They have always wanted to fuse my ankles but I have resisted and instead exercised them to the extreme. I am so glad I did this now. Treloars wanted to fuse my ankle joints.

73. I have had to have a lot of work done at the dentist and still do. When I go, it's usually to have extensive treatment. These days I use the community dentist, I have found they are quite well informed and I always let them know what form of FVIII I have in me if I believe I'm going to have a procedure that may lead to a bleed.

74. The impact this has had on my life is a big unknown question mark. It has affected my relationships, working life and general well being. My life has been a continuous cycle of cause and effect. This statement is the first time I have ever spoken to anyone official about what's happened to me.

75. It wasn't until I cleared the virus that I realised what an effect it had had on my life. Once I had cleared it my ability to think clearly, process information and my mental capacity improved drastically.

Section 6. Treatment/Care/Support

76. I was under the care of GRO-D when I lived in GRO-D I attended GRO-D Hospital to see her. To manage my haemophilia during this period of my life I was under the care of Dr GRO-D and GRO-D

77. GRO-D is an obnoxious woman; she was a type of doctor that expected me to accept what she told me because she knew best. I have heard horrible things about what she's done to people.

78. She was one of the people to say that haemophiliacs GRO-D GRO-D She always thought she knew best. She worked for what was probably one of GRO-D haemophilia

centres in the UK when I was under her care and under that guise she constantly disregarded haemophiliacs like myself.

79. She expected us to be grateful for what had happened to us. She has done more negative than any positive she ever might have achieved in her career. She scoffed at the idea of GRO-D for the Haemophiliacs who had been infected with contaminated blood. I know this as I had a conversation with her about it. She alluded to the fact that we should all be grateful for the treatment we received and that we were not dead as a result of the haemophilia. This conversation took place sometime between 1994 and 1997.

80. GRO-D s treatment of me was negligible, she never listened to me and I was very happy to move away from her once I moved from Redhill to Bordon in Hampshire. Once I moved I was back under the care of Dr Wasef and Dr Roy and the nurses I had known before at school.

81. My current GP is a good bloke and is aware of my history. He is in awe of me so he obviously knows other people in my position who aren't as capable as I am.

82. My first round of Hepatitis C treatment occurred at Basingstoke Hospital. I cannot remember exactly when. I was under the care of Dr Brookes at this time and she put me on a course of Interferon, Ribavarin and one other drug, the name of which I can't remember.

83. I had been putting the treatment off for a little while because I had been warned about how bad the side effects were and I was doing things in my life at the time which meant that I didn't want to entertain the side effects. However just before I started the treatment Dr Brookes advised me that I was approaching the point where I had to start the treatment before it was too late.

84. I injected the Interferon into my stomach and took the Ribavarin and other drug in tablet form. I had an absolutely horrible reaction to these drugs, the first round of treatment was awful. My skin became loose, it was a very strange experience and one that is hard to explain and put into words.

85. I barely slept, I was manically depressed to the point that I was suicidal and I went on Citalopram to try and get me through the treatment. My teeth seemed to deteriorate really quickly and hurt a lot more, they felt horrible and my gums receded. I visited the dentist very frequently during this first round.

86. The treatment made no impact on my viral load; I was on it for a few weeks before I was taken off because it was making no difference. It took me about a year to recover from the first round of treatment. My loose skin went away pretty quickly but my mental disquiet didn't go away for quite a while.

87. I wasn't working during this first round of treatment and my days were filled with sleeping. I think this was due to a combination of the hepatitis, treatment and depression and it absolutely ruined me. I thought it was going to die, my liver was becoming more and more of a problem and the treatment had no effect whatsoever.

88. The depression I felt during the course of treatment was like a manic suicidal depression, but after I came off the treatment I was more conventionally depressed for a couple of years. I eventually weaned myself of the Citalopram and felt a lot better once I had.

89. I believe my second round of treatment began in 2014, I was under the care of Queen Alexandra Hospital Portsmouth, Hepatology department.

90. I was on a different course to the first time, which didn't involve Interferon. I cannot remember exactly what I was on. If it becomes relevant I give the inquiry my permission to access my medical files. The course I was on consisted of tablets which lasted 12 weeks. The side effects were crazy again my skin was loose and the suicidal thoughts came back and I went back on the Citalopram.

91. At first I thought it wasn't going to work again but eventually the doctor's told me the drugs were making a difference and that changed everything.

92. The second round of treatment helped to diminish my viral load which took a hell of a long time to sink in, during which a sense of well-being crept in and my mental clarity improved.

93. I was told I was clear of Hepatitis C around 2014 when I was about 39/40 years old after being diagnosed with the virus when I was 15. It defined me for 25 years. I cant imagine what my life would be like or the person I would be if I never had it.

94. I've had fibro scans at Queen Alexandra's throughout the years. I was always told that I was just below the danger zone for liver damage to a haemophiliac who occasionally drinks. But I have found that my results from the fibro scans have been very varied.

95. In the months after the second round of treatment I had some very good results but also some very bad results so I have realised that fibro scan results are not to be trusted and are very much operator dependent result based.

96. Now I have regular blood tests and ultra sounds to check my liver function and as it stands I am stage 2 liver disease.

97. Eventually after I cleared the virus I started to think about work, I fell in and out of a few things before getting my current role which I have been in for 18 months.

98. I still think my levels of fatigue are caused by the virus and my liver problems. When I come back from work I am absolutely beyond knackered.

99. I have told my employers that I am a haemophiliac but I have been selective about what else I have told them. Notwithstanding this, I am content for my identity to remain on this statement. I will deal with any future issues with my employer if they arise.

Section 7. Financial Assistance

100. I was told about the Skipton Fund by my haemophilia consultant at Basingstoke Hospital, Dr Brookes. She helped me fill out the application forms and signed them off. I received the initial grant of £20,000 in 2005 and had no monthly payments at the time.

101. Upon my stage 2 liver cirrhosis diagnosis I received a further £50,000. From that point I received £15,000 a year which has now gone up to £28,000.

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GRO-C

103. GRO-C

GRO-C

104. The premise of the Skipton Fund (now EIBSS) is good and I understand that they're trying to provide financial support but there shouldn't be a need for it in the first place. I never feel like I'll be fully compensated.

105. Back in the 1980s the Republic of Ireland would have compensated a haemophilia sufferer to the sum of about £860,000. If you adjusted that figure to reflect today's economy, it is a lot of money and truly reflects the damage done which would be true compensation instead of the piece meal we have received to this date.

Section 8. Other Issues

106. I have never had the chance to forge a career for myself but I know that if I had been afforded that opportunity I would have succeeded at it.

107. I have no doubt whatsoever that my personal relationships have suffered as a result of the Hepatitis C infection at such a young age, I was very reticent to become involved with girls because of all the explaining I would have to do.

108. I believe my wife actually wrote to one of the consultants at the hospital asking him about the risk of infection before we were married.

109. I work now because I can afford to health wise, I get paid £25,000 a year from my current role and if that was my only income I

would struggle to live. I know I do better than my colleagues for whom the salary is their only income; they know I get the financial extras.

110. It took me a long time to find my voice because I have always felt so subhuman and voiceless. I would never have taken on the responsibility of explaining to a friend or a colleague my situation before, but things are different now and I am more open.

111. I have lived my life by psychologically blocking things out and now I am very stubborn and stoic, I refuse to be hindered by pain or pressure.

112. I know people from school whose joint problems are shocking, some of them are in electric wheelchairs and others are lock legged. A lot of them were fused at Treloar's and sometimes this had to happen multiple times. I always resisted being fused, but I had to fight for it.

113. I am 43 years old, I don't know how much longer I have and sometimes I worry about the state of my liver. The time for hiding has gone.

114. An admission of liability by the government would open the door to an extra compensation claim. The fact that the government has never admitted liability really sticks in my throat.

115. Kenneth Clark is the man who was responsible at the time, he was the Minister for Health and to me, he and the NHS are all tied together. He should be in the firing line. If you look at the Japanese and French governments, people went to prison. The same needs to happen for us.

116. I want further compensation and an admission of guilt and liability, nothing more.

117. Everyone who stayed in Guernsey was never affected as they sourced their blood under different guidelines. My life could have been very different if I stayed.

118. The last time I was there which was very recently there was a full-page spread about the Inquiry in the local newspaper. It's interesting to me that the contaminated blood issue is permeating over there.

119. Given the opportunity, I would like to speak at the public hearings.

Statement of Truth

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

Signed GRO-C

Dated 03/07/19