Witness Name: Richard Hone
Statement No.: WITN5564001
Exhibits: Nil
Dated: 20/2/22

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF RICHARD HONE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20 October 2021.

I, Richard Hone, will say as follows: -

Section 1. Introduction

1. My name is Richard Hone. I was born on GRO-C 1970 and my address is known to the Inquiry. I work as a Test Engineer for a national engineering laboratory, primarily working in oil and gas. I live in Glasgow with my wife of 10 years. I have two grown-up daughters aged 23 and 25 from a previous marriage. I intend to discuss my infection with Hepatitis C (HCV) which I contracted from blood products for treatment of my Haemophilia.

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

3. I can confirm that I have chosen not to have legal representation and the Inquiry Investigator has explained the anonymity process to me. *I do not wish to be anonymous.*

4. I can confirm that I have not been involved in any prior litigation.

5. I can also confirm that the Inquiry Investigator has explained the 'Right to Reply' procedure, and that if I am critical of a medical professional or organisation, they will have the right to reply to that criticism.

6. I wish to acknowledge that naturally as time passes, memories can fade. I have therefore been able to provide approximate timeframes for matters based on life events. However I can only recall to the best of my ability, and these timeframes should be accepted as 'near to' rather than precise dates.

Section 2. How Infected

7. When I was an infant, I was bruising more than expected. My parents took me to the doctor and I was referred to the Royal Hospital for Children, Glasgow, which we knew as Yorkhill Children's Hospital.

8. I had tests and by the time I was a toddler, I had been diagnosed with Haemophilia B. We had no family history of haemophilia, so the news came as quite a shock to my parents.

9. I have a brother and sister, but sadly my brother has passed away. My brother and sister have a different father to me. They have never been impacted by haemophilia.

10. I was never coddled as a child. My parents were never very worried and they didn't feel guilty, nor should they. I don't blame them for my haemophilia or what happened as a result of my treatment for haemophilia, it wasn't their fault. They treated me very normally and I used to get clipped around the ear as much as anyone else did.

11. I was also quite normal and that meant the rough and tumble of youngster growing up. I would often fall over and cut myself or suffer bruising. However, as a result of my haemophilia, this meant I had to spend a lot of time in

hospital for treatment to help me control my bleeds. Fortunately I didn't mind hospitals. I would be put on plasma drips. This was different to cryoprecipitate which I am not aware of receiving.

12. In the early 1980s, when I was around 10 years old, concentrated Factor IX was the treatment hat became available.

13. At the time, this felt like a godsend as it meant I could be treated at home. At first, my mother was taught to give me the injections. As a boy, I had been a regular visitor to the Yorkhill Haemophilia Unit, but being able to be treated at home with the concentrated Factor IX meant my hospital admissions were significantly reduced.

14. We had to go in to collect the Factor IX from the hospital every few months or so. We would bring it home and keep in the fridge and then take it out and use it as and when I needed to.

15. I was lucky in that I didn't have to inject all that regularly, around once a week on average, and the volumes injected were relatively small.

16. When I was around 12 years old, my care was transferred from Yorkhill to the Glasgow Royal Infirmary.

17. In my early to mid-teens, even though I was on the home treatment, I was still in hospital quite a lot. This was because I would still have to be admitted for bad bleeds.

18. This affected my school work as I had to take a lot of time off for hospital treatment. I therefore didn't leave school with very good qualifications.

19. I was able to get a job, and I began working at my current company in 1989.

20. I married my first wife in 1994 and we went on to have our two daughters and life was normal. I continued with home treatment when required.

21. In the late 1990s, I was called in to see one of the doctors. It would have been either Professor Lowe or one of his team but I can't remember exactly who it was. It was at that meeting I was given the news that I had HCV. There is nothing that I particularly recall being wrong with me prior to this other than problems associated with my haemophilia such as my joints.

22. When I was told about the HCV, the doctor mentioned the blood products I had been getting could have been infected.

23. There are no other ways I could have become infected. I have never been intravenous drug user. Although I have always wanted a tattoo, I do not have any, nor do I have any piercings. I have never been medically treated abroad and at the time I was happily married.

Section 3. Other Infections

24. I have been tested for HIV and this was negative.

25. I had regular routine appointments, twice a year, and I had blood tests each time. I knew they were testing for HIV. I asked for this as I was seeing the news, and I wanted to know.

26. I wasn't aware they were testing for HCV. I didn't even know it existed until I was told I had it. Being given that news was like a sledgehammer in the face. The risk from HIV was always present and a worry but there had never been any indication of this potentially lethal infection and my heart just sank.

27. Later, in 2010, I received a letter about the risk of vCJD. This felt like an extra kick in the face.

28. The letter said that someone who had donated blood had gone on to develop vCJD.

29. I found this letter very distressing as did my wife. It brought it all back for both of us. I thought I'd done well to get over the HCV and had put it behind me, only to then get this. You just think what's next? Why send it? The letter actually said they could do nothing for you if you contracted it anyway.

Section 4. Consent

30. I do not recall there being any discussions about the risk of Factor IX or plasma neither with me and I do not recall my parents ever mentioning they had been informed about any risk involved.

31. My earliest memory of concentrated Factor IX was that it was a life-changer; this new treatment was a good thing. I was told I can use it before a bleed, and I wouldn't have to go to hospital for treatment as often. That's how it was sold to me.

32. As mentioned above, I was not aware that I was being tested for HCV, and so therefore did not provide my consent to that.

33. I don't think any treatments have been experimental nor do I believe that there was any treatment available that was withheld from me.

Section 5. Impact

34. When I was a child, it was suggested to my parents that I should go to a special school and wear a special helmet. As far as I am concerned that would only have attracted unwanted attention and would not have been in my best interests. Thankfully my parents kept me in mainstream education.

35. However, my schooling was undoubtedly affected, though this was probably more to do with haemophilia than HCV. Even after the introduction of the home treatment, I was still having to spend extensive periods in hospital

which meant missing lots of school. This definitely impacted my school work and resulted in me not coming out with the qualifications I would have liked. The disruption was just too much.

36. I recall, I even did one of my exams in hospital; I was put in a room by myself and had to write the exam on the ward.

37. I did go to college and I did okay once I was older. By then I wasn't in hospital so much, which meant I was more able to apply myself to studying.

38. In terms of employment, holding down my job has at times been a struggle, particularly during my HCV treatment. It was like having a bad hangover 3 times a week that I just had to work through.

39. I kept it all to myself. I didn't disclose to work about the HCV or treatment. I just did my best to soldier on.

40. I don't recall having any more time off than usual. I tend to have a certain amount of days lost due to bleeds anyway. I still get flare-ups from old bleeds. For example, my ankle flares up, and I can't walk for 3 days. I have to just rest it and wait for it to calm down.

41. I have worked for my current company since 1989, so 32 years now. I chose not to disclose my HCV status to my colleagues due to the stigma. People tend to conflate HCV and HIV with drug use.

42. By the time I was diagnosed with HCV, we were past the 1980s with the shocking adverts about AIDS and all the doom and gloom, but the knowledge generally at the time was still that HCV was connected to drug use. I didn't want to be associated with that.

43. I was in my 20s when I found out about the HCV, and at that time, I wasn't particularly confident. This also contributed to me just wanting to keep it to myself. I ensured my then-wife was aware, but I didn't tell other people.

44. As result of the HCV, I lost a lot of confidence. I feel like I have been held back because of it at work. For example, I felt I wasn't able to go for promotions or move workplaces in order to move up the ladder. My career progression and finances have been significantly impacted as a result.

45. On Facebook and other social media, I see people in similar situations to me talking about their lives. I sometimes feel lucky how things turned out for me in comparison to others, who in my opinion, have had it even worse.

46. I therefore try not to think too much about things like how the HCV has held me back, and focus on the fact that a lot of people are a lot worse off than me. Over the years, I have spent a lot of time with my head buried in the sand, trying to avoid thinking about certain things, which can cause problems in the long run.

47. All my life, I have been determined not to be defined by an illness. I have spent my whole life trying not to be a haemophiliac. Having to deal with HCV on top of my haemophilia, was devastating.

48. As such, I don't tend to have much to do with the Haemophilia Society. My first involvement with the Haemophilia Society was only a couple of years ago and was a Haemophilia B focus group.

49. In terms of relationships, the HCV undoubtedly accelerated the breakdown of my first marriage. The relationship was on a decline from when my second daughter was born, and in 2002, my first wife and I separated.

50. How she felt about things was not positive, and we had a lot of arguments and negative discussions, and eventually our marriage broke down completely.

51. She had difficulty accepting the HCV. She questioned how I came by it to an extent. It made her suspicious. This carried on even after I was successfully treated.

52. I was always clear that the HCV was not from homosexuality, promiscuity, or drug use or other risky behaviours. However she still had a hard time getting her head around it. Thankfully the HCV hasn't affected my relationship with my daughters.

53. After the break-up of my first marriage, my mindset was still affected by my experience with the HCV, and meeting another partner was difficult. It was hard to get relationships to stick. The question of how – and when to broach the subject is always in the back of your mind.

54. The HCV continued to affect my behaviour, for example, when I was dating, I would never have a one-night stand with someone, even though I knew I had cleared the virus.

55. Furthermore, when I meet some-one I am interested in, I always have to measure how to deal with them, and as mentioned give consideration as to when that certain uncomfortable conversation should take place.

56. I have to think about how and when to tell them first about my blood disorder, haemophilia, and then I have to disclose the HCV. There certainly was, and still is a stigma whereby many people think it's like HIV and it undoubtedly put a lot of potential partners off.

57. I had a lot of very short relationships, before I met my current wife. I had the conversation with my current wife quite early on in our relationship. She was understanding, and she continues to be really good about everything and consequently I have really opened up about my past experiences to her.

58. My current wife and I have been together for 15 years now, and married for 10 years. Initially, the HCV caused some difficulties within our relationship, for example, it led to some tough discussions around having children. We ended up choosing not to have children.

59. The HCV certainly influenced our decision not to have children, and I have some regrets about that now. My wife has a good understanding of the condition but it is still an ever-present worry for her. We both worry whether the HCV will return and what any consequences of that may be.

60. In my friendship and family circle, most people I know don't know I had HCV. This is due to the stigma and my desire to keep my information private. Most acquaintances don't even know I have haemophilia, as I tend to keep things to myself. You learn through experiences to be more guarded about what you say.

61. I was in my mid to late 20s when I found out about the HCV, so I had moved out of my family home. I moved out at 19. I never discussed my HCV with my siblings.

62. My daughters don't even know I had HCV. I tend to be very careful who I tell things to, and I don't believe it is helpful for them to know.

63. In respect of both my career and financially, I lost a lot of confidence as a result of the HCV. Having HCV made me think I should stick with what I had – the safe option, the one I knew and therefore I have not gone forward for promotions even if I had a good chance.

64. After getting divorced I had to start again. We had to sell the house, and I had to find another place to live. Having been financially comfortable, I dropped back several rungs down the ladder after my divorce.

65. I couldn't get life insurance. I applied for it when I got a mortgage, but I couldn't get it. The cost would be around 10 times higher than average, which was prohibitive. Life insurance is basically a no-no.

66. I have been able to travel and have just been lucky nothing bad has happened as travel insurance is also very tricky.

67. As I mentioned, the HCV has meant I have always had to steer the safe course rather than take risks and move on in other directions. It has held me back promotion-wise and in respect of preventing me from moving to other job opportunities. However I count myself lucky that I have even been able to hold a job down for as long as I have.

68. I have tried for many years not to think too much about it all and to just get on with my life. However it got to the point where I wasn't coping anymore. I have had this in my head for years. Obviously because of the Infected Blood Inquiry, over the past few years, it's been pushed to the forefront.

69. The HCV has affected work, relationships, and my confidence. It has had a huge and consequential impact on my life.

70. Even though I have cleared the HCV, I know there is a chance it might come back. As mentioned, this is always at the back of my mind.

Section 6. Treatment/Care/Support

71. When I was given the news about my HCV infection, I was given the information face to face. The doctor made a spiel about it all. He said a bit about the blood products I had been getting could have been infected.

72. Before they tested me, I believe that they knew I had it. This was due to the results of liver function tests I had been having leading up to being actually tested.

73. I had regular routine appointments, twice a year, and I had blood tests each time.

74. I knew they were testing for HIV. It was very much in the public eye at the time so I was very aware, and I wanted to know if I had been infected. I would

therefore ask to make sure I was being tested for HIV. I was starting to think about having a family, I didn't want to infect my wife.

75. I wasn't aware they were testing for HCV. As I've said, I didn't even know it existed until that point. It was a complete shock. The doctor said it could kill me, so I knew immediately it was serious, however I didn't know exactly what the implications would be.

76. No leaflets were provided, and I do not recall being told what I could do next or what to expect going forward. For example, I don't recall any information or advice regarding precautions being given to me. When I was first told, I did have it in my head that this could be like HIV, but this was my own thinking rather than what was actually being said to me. I do not think any treatments were mentioned at the time either. It wasn't until some time later, I was told about Interferon.

77. After receiving the diagnosis, I wasn't given any more monitoring than my usual 6-monthly appointments. This was still at the Glasgow Royal Infirmary.

78. The next step was when they said they had a treatment that I could try. This was in 1999.

79. I agreed to start the treatment. It consisted of a combination of Interferon and Ribavirin; the Interferon was injections and Ribavirin was in tablet form. Professor Lowe was in charge of my treatment, and the treatment was managed by a nurse in the liver unit at the Glasgow Royal. I can't remember her name.

80. I didn't have a lot of direct dealings with Professor Lowe, as usually I was seen by his staff doctors. Every time I did deal with him, it was positive.

81. The treatment regime was intense. I had to have the subcutaneous injections every other day and I had to take around 7 tablets a day. I was on the treatment for nearly a whole year; 50 weeks.

82. Prior to starting treatment, I was tested to see which genotype I had. I believe it was 1A. The type I had was one that required the 50 week treatment at that time.

83. I never had a biopsy, though I have had some ultrasounds. I have had a fibroscan in the last couple of years, but not at the time.

84. My vision started to deteriorate. I required glasses in my mid to late 20s. This could be attributed to virus. Prior to my diagnosis I can't recall any visual symptoms and it is not an inherited trait.

85. I have had joint problems but I believed this was more down to bleeds than the HCV. My left ankle is the worst, and I also have trouble with my right knee.

86. I have spoken to my doctor at the haemophilia unit extensively about this and I am aware the HCV could have worsened my joint problems.

87. Half way through the course of medication they couldn't detect the virus, but I had to complete the second 25 weeks. I had been told if I hadn't cleared it after 25 weeks, I would never clear it, so the news the virus was undetectable at 25 weeks was very encouraging.

88. Thankfully, I made it to the end and the treatment was successful. It is hard to explain the feeling of relief to have the burden lessened.

89. The treatment itself was horrible. It felt like having a hangover most of the time. It made me moody and grumpy. It caused me to feel fatigued and lethargic and disrupted my sleep pattern. I wasn't a nice person to live with for a year and although possibly not completely responsible, this undoubtedly accelerated my marriage break-up.

90. The doctors kept trying to give me different advice about when to have the injection in order to minimise the side effects, particularly on my sleep pattern.

I tried taking it just before bed, but this didn't work. Then I tried during the day, but it also didn't make any difference.

91. I developed psoriasis, including in my scalp, which I never had before. This all came on during treatment. My rheumatologist thinks I have psoriasis induced arthritis as a result.

92. I also had haematuria, which was unexplained blood in my urine. My doctor at the haemophilia centre has since mentioned that could have been as a result of the HCV.

93. I didn't realise how bad I was, and how much I had been affected mentally and physically. There were physical manifestations of the HCV that I hadn't ever really even contemplated. For a long time, I thought HCV only caused liver complications. I didn't realise it affected lots of other things as well.

94. I had compartmentalised everything and I buried my head in the sand, for decades.

95. Last year, I developed a problem with my stomach. This has not yet been properly investigated as I am still waiting for an appointment with a gastroenterologist. The waiting period has been extra-long because of the coronavirus pandemic.

96. I have been having pain and issues after eating. I still get liver function tests and blood tests every 6 months, and at present, my liver function tests seem okay, but there is always a worry in the back of my mind that there might be something wrong with my liver as a result of the HCV infection.

97. I never went to GP about my mood swings or mental health as a result of the treatment, I chose to deal with it myself, though looking back, I actually didn't really deal with it.

98. I have only recently had some counselling. Dr Alvi at the Royal Infirmary has been very helpful. He got me the psychological counselling in the last year. However there was never the offer of counselling at the time I was diagnosed or during treatment, to either me or my family.

99. I was very glad to be finished with treatment. It had got to a point that I couldn't take any more of it. It really pushed me to the edge. It drains you both physically and mentally and to an extent consumes you.

100. I don't recall having suicidal thoughts during my treatment, but I definitely had a few dark moments. The worst I felt was that I suddenly understood why people killed themselves. It suddenly made sense to me.

101. In the last decade, my mental health has declined. Recent counselling has helped. However I have had to wait since the late 1990s/2000 for counselling, which means over 20 years. The pent-up emotions that infection and then treatment stirs up eat away at you and I can understand why so many spiral into depression.

102. Counselling doesn't make the problems go away, but it does help. It doesn't cure the issues but gives the tools to cope with them.

103. I have never had any issues with the dentist. I use Townhead Medical Practice which is based in the hospital. I have never had any problems with accessing dental treatment.

104. Before the HCV treatment, whenever I would go to any appointments and have blood taken at the hospital, everything was labelled with 'biohazard'. I first noticed this at the haemophilia unit. It was obvious enough for me to notice without looking hard. I know why they do it, but it's not pleasant.

105. I have never been treated differently as a result, for example I have never been isolated when in hospital.

106. They may have used extra PPE when taking blood. This is not recently, but further back.

107. My treatment was quite early, and I know subsequent treatments aren't as harsh, which is a good thing.

108. I had got married in 1994, before learning about my HCV status. I didn't find out about the HCV until the late 1990s. No one ever suggested that my now ex-wife should be tested. As far as I am aware, she has not been tested, but I am not sure about this.

Section 7. Financial Assistance

109. I came to find out about the Skipton Fund from someone at the Haemophilia Unit, though I don't remember who exactly.

110. I got an application form which I filled out and then Professor Lowe signed my application. I didn't have any issues with the form or process.

111. I applied in July 2004 and they paid out in October 2004.

112. I received £20,000, which was the first stage payment. I was at my lowest level financially at that point, so I was very grateful for this lump sum.

113. My recollection is that they were saying 'it's not our fault but here's some money', so an ex gratia payment, but I don't recall having to sign a waiver.

114. Some-time later, after a few years in fact, Dr Alvi helped me with applying to the Scottish Infected Blood Support Scheme for personal payments. Up until then I had received no on-going support.

115. I now receive around £2,300 per month from the SIBSS.

116. Before that I got £30,000 as a lump sum. This was a few years after the initial payment, in around 2010-2011.

117. I didn't do anything for that, it was just given to me.

118. I was getting nothing before, and am not very clued up so I don't have a relative position to be able to comment on the financial support available to me although I am grateful to receive it.

Section 8. Other Issues

119. When the Infected Blood Inquiry first started, and then afterwards whenever there has been coverage in the news, people who know I have haemophilia start to ask questions.

120. I am often apprehensively waiting to be asked if I was infected. The Inquiry has brought the situation to the fore which brings negatives as well as positives. I usually try to change the subject when it comes up or, alternatively, I move away from the conversation. It's horrible and it makes me very uncomfortable.

121. Furthermore, the Inquiry has brought up a lot of memories that I have tried not to think too much about or speak about throughout my life. Initially I didn't want to talk about it, however, as time has gone on and the Inquiry has progressed, I decided I did want to contribute. My motivation is solely to help other people understand. Possibly my story can help someone come to terms with their situation.

122. With respect of the whole infected blood scandal, I don't have much to say apart from that people have gone to jail for less.

123. I am not a vengeful person; I don't seek vengeance. I seek justice. This is not for me, as I feel I got off lightly compared to a lot of others. I do, however, want to see justice for the families of people who have died.

124. The whole experience has affected my confidence in the NHS. I have ended up with a dual feeling; I have a lot of respect and confidence for the doctors and nurses at the coalface. I generally have a lot of faith in them. However with regards to the managers, politicians, decision-makers; I don't have much faith in them at all.

125. I feel like what happened to me was because of them. Some of those people must have been involved in the decision to import blood, which turned out to be infected. On the other hand, the treatment from doctors and nurses has generally been very good and I am very grateful for it.

126. I am currently in the process of getting onto a gene therapy trial. It's an American pharma company and is run through the Royal Infirmary. I believe Dr Catherine Baggett is in charge of it.

127. The treatment trial aims to raise Factor IX levels in Haemophilia B patients by injecting them with an infusion of viruses that live in liver.

128. The virus is inactivated so that it is unable to cause a viral infection in humans. This inactivated virus is called 'the vector'. It is then further altered to carry the Factor IX gene.

129. This is then injected into the patient in an infusion. The vector will migrate to the liver which is where Factor IX protein is made, and so will encourage the patient to make more Factor IX.

130. I am currently in the lead up to starting the trial treatment. For six months, I have to closely monitor my Factor IX levels and record every time I have a bleed or have used Factor IX product. I have to fill out an app on my phone every day to communicate these results to the doctors running the trial.

131. I have to be tested to check I don't have antibodies for the virus I will be infused with, as well as checked for any other stray viruses in my body that might interfere with the process. I have therefore had lots of blood tests as well as other tests. In fact, I have to get all bodily fluids tested before and after. The trial procedure also included a fibroscan.

132. The treatment has been around for around 10 years, and it is something I have been following closely. I've tried to get onto this trial treatment before, but have been disappointed a few times.

133. I believe it's been improving all the time, and people seem to be getting more responsive. The treatment doesn't bring Factor IX up to normal levels, but should significantly raise the amount, which would of course be of benefit to me and the whole Haemophilia community in the long run.

Statement of Truth

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

Signed GRO-C

Dated 20/2/22