Witness Name: Paul Thompson
Statement No.: WITN0954001
Exhibits: **WITN0954002**
Dated: 3rd March 2020

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF PAUL THOMPSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 14th May 2019.

I, Paul Thompson, will say as follows: -

Section 1. Introduction

1. My name is Paul Thompson. My date of birth is GRO-C 1965 and my address is known to the Inquiry. I am a haemophiliac and I live in GRO-C London. I have worked as a Crime Scene Examiner with the Metropolitan Police for 29 years. I intend to speak about my infection with the Hepatitis C Virus ('HCV'). In particular, the nature of my illness, how the illness has affected me, the treatment I have received and the impact this has had on my life.

Section 2. How Infected

2. I was diagnosed with haemophilia A at 11 months old. As I have understood it, from my mother, this was discovered after I cut my

tongue. I was crawling around in the kitchen and I licked a can that had been dropped on the floor. I was taken to hospital where I was given stiches. When the stiches dissolved I started bleeding again so I had to go back to hospital. My local hospital subsequently referred me to Great Ormond Street Hospital, where I was diagnosed with Haemophilia 'A'. There is no history of Haemophilia in my family, so there had been no reason to suspect that I might be a haemophiliac. We now know my mother is a carrier but there is no other history of it in the family.

3. From a very early age, I can remember having to go to Great Ormond Street Hospital frequently for treatment of my haemophilia. I had severe haemophilia A, which in my case meant that I had less than 1% of Factor VIII in my blood. This meant once every two weeks I would need to go to Great Ormond Street to receive whole plasma initially, then cryoprecipitate.

4. I can remember the process quite well. I would go to the Haematology Unit and they would inspect my bruises and say I needed cryoprecipitate. They would then get the cryoprecipitate bag out and warm it up in the bath. Once it was warm enough they would administer it. I can still picture it all draining out of the bag. It would take a while and they would use large 100ml syringes.

5. Sometimes we would have to go to Great Ormond Street in the middle of the night if I had hurt myself. As I got slightly older, this made me feel like I was becoming a burden to my parents. I would occasionally hear them arguing and I felt like that was my fault because we were having to set off for Great Ormond Street so often. I remember getting bruises and not telling anyone deliberately and they would get worse and worse. I think this was because I was trying to avoid trips to the hospital. I remember the haemophilia also caused my family problems early in my life because when my dad would pick me up and play with me I would bruise so easily that the authorities thought he was abusing

me. However, this was dismissed very early on. It was just a case that my Dad didn't know how to treat a haemophiliac.

6. My parents started treating me at home at around the age of 8 or 9. I can also remember my mother coming to school to treat me. I remember before starting secondary school, I went with my mother to see Professor Hardesty at Great Ormond Street and he said "Paul has two choices, you can either let him try and live a normal life or you can send him to a special school for haemophiliacs. I would recommend you do the first" I now know more about the establishment to which my doctor referred; Treloar's School and what happened to the children that were sent there. I consider myself so fortunate not to have been sent there. GRO-D

7. Around the same time, my treatment was transferred to the Royal Free Hospital. Where initially I was treated by Dr Kernoff, then Dr Tuddenham and for the vast majority of my time Dr Christine Lee. I know that Dr Kernoff died GRO-A at some point and that Dr Lee retired about nine years ago. Dr Tuddenham later became involved in gene therapy. The staff at the Royal Free Hospital were keen for me to learn how to treat myself. However, I can't remember at exactly what age I began self-administering Factor VIII at home.

8. I can remember on the first day of secondary school, I had to go and see the headmaster with my parents. I can remember this day clearly. The headmaster said I was really lucky to get into the school because I wouldn't have got in based on my academic ability. I think Professor Hardesty at Great Ormond Street Hospital had written to the school to say that, because of my haemophilia, I would need an education so I could get a job in an office. In other words, I couldn't be at a school where I would be destined to be a plumber or labourer. I can remember then being take up in front of the whole school by the Deputy Head. He said, in front of hundreds of children: "This is Paul, he is special so don't touch him." It was an awful thing to do and from that day on

people would say, "oh don't touch him, he's got the lurgy" and hurtful things like that.

9. It felt as if my teachers were just as terrified about my haemophilia. I remember they wouldn't let me do sports classes so the sports teacher would make me sweep the training room up while the rest of the class were on the playing fields or in the gym.

10. I was definitely self-administering my Factor VIII by this point and I remember one day I was sweeping up in the changing room and I dropped my Factor VIII in the middle of the room. It was in my bag, I had gone to get something out and the bottle dropped out onto the tiled floor. The teacher went completely mad and made such a big fuss about it. It felt like I was constantly singled out by certain teachers and they emphasised the negatives of my condition rather than trying to help me 'fit in'.

11. I remember one occasion, in the tennis courts, thy other boys were playing football and I was standing and watching because I couldn't be involved. I remember the ball got wedged in the fence by where I was and they all shouted: "kick it back" and "I bet you can't kick it". I thought, "I'm going to show them", but I missed the ball and hit the metal fence. I broke my toe, started bleeding and had to go to hospital. In addition I compounded the way my peers felt about me. This example just emphasised my lack of sporting ability, because I was never given the chance. As I was unable to do contact sports, my dad and grandfather got me into nature and I became interested in fishing. This is still one of my favourite hobbies.

12. I tried to not to let all of this affect me too much but clearly, I was different from the other children and I was aware of that from a young age. I was certainly made to feel like that too.

13. As I grew older, it became clear that some people who I thought were my friends, turned out not to be. They didn't avoid me but I would never get invited to parties. Looking back, this might have been something to do with their parents. I felt like a liability.

14. I missed a lot of school which is why I was never academically very good. I remember that in junior school, I had to have extra lessons to try and help me pass. My school reports would say that I tried really hard but that I wasn't very good. I still have many of these reports. I can remember that I used to go and cry during maths lessons because I knew I was so rubbish at it and this just exacerbated the view that others had of me and also the way that I felt about myself.

15. Despite the above, I have never been bullied, I feel like my schooling and my childhood were very good apart from the moments I have set out, especially in comparison to some other haemophiliacs, such as those who went to Treloar's school. I remember one of my junior schoolteachers was the most amazing teacher I ever had. I kept in touch with her and in the school holidays she would take me out with a group of children on canal boats. I used to love being out on the boat and being with animals. So looking back, although there were some horrific moments in my childhood, in some ways I realise I have been very lucky and people have looked after me. I think once I got to around 17-18, other people finally realised that I wasn't that different, I could do things, I just couldn't play football and rugby.

16. I remember being diagnosed with the HCV in 1976, during my first year of secondary school. I had been off school for the holidays and when we went back we were given our vaccinations. The nurse noticed that I was quite yellow and so she became quite worried and phoned my mum. My mum took me to the Royal Free Hospital and not long after that I can remember them saying, "Paul has got non-a non-b hepatitis". I don't know what was explained to my parents or me at the time of the diagnosis but I can remember the horror on my mother's face.

17. The haemophilia itself was hard enough to live with on its own but when you find out you've got a life threatening infection, you feel much worse. I don't know if my parents were ever told that HCV was a death sentence at the time of my diagnosis but I suspect they were.

Section 3. Other Infections

18. I have been tested for the Hepatitis B Virus and the Human Immunodeficiency Virus on many occasions. I used a lot less Factor VIII than an average severe haemophiliac and Dr (subsequently Professor) Christine Lee explained to me that it was because of this I was kept on Factor VIII produced by the Blood Products Laboratory ('BPL'). The way I understand it is my body can multiply Factor VIII so I needed less overall. I was therefore given BPL products because they were safer and this was possible because I didn't need too much. I think this is maybe how I have managed to avoid contracting HIV through blood products.

19. I received a batch of Factor VIII, which was produced from a blood donor who was later diagnosed with vCJD. I was informed of this in a letter in around 2003 from my Haemophilia Centre. This has had an incredibly negative impact on me, which I will set out in Section 5 of my statement.

Section 4. Consent

20. I believe that I have always been treated and tested with my consent.

21. Until recently, I have always assumed that before my diagnosis I was not informed of the risks of infection associated with the blood products because the doctors at the Great Ormond Street Hospital and the Royal Free Hospital were not aware of any such risks. I now wonder if

they knew, or that they knew that there was a risk that the blood products contained HCV.

Section 5. Impact

22. After I was diagnosed with the HCV, I can remember having periods of up to two months off school because I just felt generally unwell. I felt tired and exhausted and like I almost constantly had a 'fuzzy' head. I just couldn't concentrate. I couldn't walk and I had no energy, I didn't even want to get out of bed. Because of my age, my father initially thought I just didn't want to go to school but he later realised this must be the effects of the infection. In that period of my life, between the ages of 10-14, I should have been running around and playing on bikes and things like that but I just didn't have the energy. In this way, the HCV affected my schooling and childhood immensely.

23. I struggled at secondary school because of missing so many classes. This was compounded by the academic standard, it was a former grammar school and most people went to university. Furthermore, even at school my infection with the HCV impacted on my relationships. I met my first proper girlfriend at the age of 16. When I met her parents, they were ok with me having haemophilia but once they found I had HCV around a year into the relationship, they stopped her from seeing me. They said she shouldn't be with me because of the virus. This had a massive effect on me and stopped me from allowing myself to become committed too soon in future relationships. It also made me acutely aware of the stigma attached to the HCV and I became fearful of letting people know I had the virus.

24. After finishing school, I went to work at Pinewood Studios as an assistant camera operator, working in special effects. Someone had left a job there in a rush and I was asked to fill in operating a camera. I stayed at Pinewood for around eight or nine years. We were a small, close team, we used to share everything and we would often work

together through the night. I remember one day in 1986 we were making a film for the Terrence Higgins Trust around the time that it came out that haemophiliacs were one of the high-risk groups for contracting HIV. After that, everything changed. The day before we would have shared a can of coke and the day after they never shared anything with me again. This was also the period of the scary 'Tombstone' AIDS public information films during the adverts on TV.

25. Around the same time, I fractured my skull in work. I hadn't seen that there was an RSJ in the ceiling and I jumped up and banged the top of my head. I was bleeding profusely and no one would touch me. Some of my colleagues put on massive gauntlets and just put kitchen towel around my head. Even the ambulance crew seemed really wary about helping me once I told them I had haemophilia because of the prevailing association with AIDS. After this incident, everything went downhill. My work colleagues had begun treating me differently and I realised the writing was on the wall at that work place. Thinking about leaving Pinewood Studios was difficult because I was in a good job that I enjoyed doing but I felt that the close-knit group that we were before, was no longer there and it had changed. I was looking forward to getting out of the environment but I was scared that no one would hire me when I revealed I had haemophilia and HCV.

26. I remember being very tired when I was working at Pinewood Studios, but at the time I did not attribute this to the HCV. I was working hard and cycling 14 miles a day to get to and from work, sometimes with an ankle bleed, so I attributed my tiredness to that routine. However, looking back, when I was working during this period of my life, I didn't really go out because I just didn't have the energy. I would be going to sleep at 8 or 9pm everyday when I arrived home. I now realise this was not normal and this exhaustion was at least partly attributable to the HCV.

27. My uncle was a Police Officer at Hayes Police Station. He suggested that I go out with the Crime Scene Examiner at his station and see what it was like. So I went out for the day and thought maybe this is something I could do. I first applied to The Metropolitan Police Service ('The Met') for a role as a Finger Print Officer in 1989. The first two times I applied, I never heard anything back. I thought there was no way that they would take me with haemophilia and HCV but I thought I would apply one final time. On this final occasion, I was offered an interview.

28. There were four people on the panel at my interview. I asked them in the interview: "I've got haemophilia and HCV– how does that make you feel?" I think they were a bit taken aback because they weren't expecting a question like that. They asked me why it mattered, and I explained that it mattered to me because I was in a job and at a place where it is affecting my life. They told me that it made no difference to them, or their decision. I was happy that I had been honest with them and that I had given them the chance not to hire me, if they were bothered by my conditions. I remember walking out of the interview in shock because I had thought, with haemophilia and HCV, they just wouldn't give me the time of day.

29. As far as I am aware, I became the only haemophiliac employed by the Met at that time. I remember the day when I received the letter to inform me that I had been successful. I believed it was the new start I needed. I remember looking forward to telling my employers at Pinewood Studios that they can stick their job and I would be much better in my new role. I was so thankful that someone would take the risk to employ me despite me having haemophilia. I began training in 1991 and started my job in September of the same year. To qualify as a Crime Scene Examiner, I spent five years as an identification officer, examining and matching fingerprints. At the same time, I was undergoing on the job training in other areas of crime scene work.

30. To monitor my HCV, I was having tests every six months and yearly liver scans. Around 1992, when I was 28, Professor Lee advised me that there was treatment that she wanted me to try in order to clear the HCV. I began this treatment in the last year of my training to become a Crime Scene Examiner. It was a 48-week course of therapy, which entailed stomach injections of Interferon and Ribavirin three times a week. The Interferon injections were horrible. I used to cry before administering them. I used to be able to handle intravenous injections but this was much worse. I knew that as soon as I would inject myself, I would feel so much worse so I was became worried about doing it. I would usually hesitate for around three hours and then force myself to do it.

31. It just made you feel really, really bad. I had been told that there would be side effects but if I had known that they would be that bad, I might have reconsidered whether I wanted to go through with it. I would have constant cramp and really bad back pain. My sleep was all over the place, sometimes I couldn't sleep and then sometimes I could sleep for ages. I just felt completely wiped out; the fatigue on Interferon was about ten times as bad as when I had just HCV. I remember feeling particularly bad the day after every injection.

32. I knew the Interferon was starting to work because I had regular visits to the hospital and it was clear that my viral load was reducing. However, I was told that I would need to be on the treatment for 48 weeks or it wouldn't work. About six weeks into the treatment, I had really terrible oral thrush. I couldn't drink, eat or do the most basic functions. Professor Lee prescribed me tablets to try and fix it but eventually said that because it was making me so ill, I would have to stop the treatment. Towards the end, I was really pale and everyone became really worried about me. I was hospitalised and put on a drip because I was so dehydrated. Honestly, I don't know if I have ever felt the same since this treatment. I don't know if I have just got used to

being so tired because of having the HCV for so many years but it feels like I have suffered with fatigue ever since this period of my life.

33. Professor Lee told me that genotype 1 HCV was the most difficult type to get rid of and because I had to stop the treatment, my viral load increased and the infection had came back.

34. I explained what was happening to my employers, the Met during this period and I was referred to the occupational health department. They were really supportive at work and would let me come in late if I needed to. Towards the end of the treatment, I couldn't do it any longer; I couldn't function let alone work. Management and my colleagues supported me very well. There was never any question whether I should go for the treatment. I don't mind saying that I wouldn't be here today, if it wasn't for the help of my colleagues and good friends.

35. Once I had started to feel physically better after the first treatment, I went back to work and I began a relationship with a woman in my team. However, this didn't last very long. I had been with her for around a year and then one evening she asked me to meet her at a pub in Charing Cross. When we met, she said: "I can't do it anymore, I can't deal with how constantly tired you are all the time." She was right in that I was waking up and I would feel like I hadn't slept. This was the beginning of my depression. The Haemophilia Centre told me that the depression I was feeling was as a result of the Interferon treatment. They said it makes you predisposed to depression.

36. In 1999, I was told that I should try a course of treatment again. I can't remember exactly the reason why it was suggested that I started treatment again at that time, but it may have been because of the result of my tests. I think it was exactly the same treatment as the first time because it was supposed to last 48 weeks and was exactly the same process for administering the treatment. The side effects were exactly

the same. It was reducing my viral load again, so even though I felt bad, I stayed on the treatment because I was encouraged by the fact that it was working so well. The staff at the Haemophilia Centre told me that things were looking promising but I would need to complete the 48 weeks to clear the virus. This time I lasted six months before I was hospitalised and had to stop.

37. The Ribavirin made me really snappy with the people I love. It would make me so angry and then I would hate myself for feeling that angry. I would bash my hands on my head to punish myself for being horrible to the people I love. I was beating myself up mentally and physically for what I was doing. Even stupid things would trigger me off, like if my grandma asked how I was feeling, I would fly off the hook and I didn't know why I was doing that. My grandma was also having treatment for breast cancer at the time and I knew that I was failing to support her through that. I didn't feel this way all the time but I would often snap spontaneously, for no apparent rational reason.

38. Between us, Professor Lee and I decided to stop the Interferon treatment for the second time. I just couldn't carry on with it. I remember thinking that I would rather have HCV than feel how I did on the Interferon treatment. I think Professor Lee appreciated that I had tried to stay on the treatment for as long as I could but that I could no longer handle it.

39. Work - The Met, were great to me again over this period. I didn't want to take any more sick leave because I didn't want to feel like I was taking too much, not that anything was ever said to me by any of my colleagues. I had counselling through occupational health to help me deal with the Interferon-related depression. By this point, in 2001, I had begun to have suicidal thoughts and I was put on anti-depressants.

40. I will be forever grateful to my counsellor for how she helped me during this time. I have since written to her and the Haemophilia Centre to tell

them that I credit her with saving my life during this period of depression. I also wrote to her line manager. I really appreciate the help that I was offered through my work and everything they have done in tolerating what I have been through and how it has hindered my work. As a demonstration of the level of support I received, my line manager used to drive me up to the counselling sessions in his own car, wait outside while I was having my sessions and then drive me all the way back.

41. I was offered my third course of treatment in 2002. This time it was Pegylated Interferon and I was told that it would still require 48 weeks of treatment but that I would only need to take the treatment once a week. I still had to take Ribavarin tablets daily. I was also told that the side effects wouldn't be anywhere near as bad. For obvious reasons, Professor Lee was concerned for me because of the depression I had suffered during and after the previous treatments. I decided to accept the third course of treatment but, anticipating how bad I would feel once it started, I decided to first go on holiday to Canada for a two-week fishing holiday.

42. The day I was due to leave Canada I was in a bookshop and saw a book called 'Living with Hepatitis C'. I decided to buy it and I read it on the plane home. The book included tips for dealing with treatment for HCV. It said to not have a bath before and after the treatment is administered and to drink water constantly like you've never done before. This book helped me so much and made the process of going through the treatment so much smoother. I put all the tips into practice and I even took the book to the Haemophilia Centre and told them they should give it to other patients.

43. After six weeks of treatment, I had cleared the HCV, but I was told that I would need to complete the full 48 weeks of treatment. At the end of the treatment, I was told that my liver had not been damaged or scarred and physically I felt far better.

44. Mentally, I was still all over the place and I suffered from long bouts of depression. What made me hate myself was that I would look at some people going through hardship, for example new parents who have lost kids or someone who has lost a leg, and I would think, "you deserve to have that". My counsellor thought that this might have been because unconsciously I was thinking that if I'm suffering with haemophilia then other people should suffer too. These were completely involuntary and uncharacteristic thoughts. I had no control over them.

45. I was still visiting Professor Lee to monitor my liver and I would ask her if the virus would come back. I was very worried about this, if I ever got sick or came down with a cold I worried that it was the HCV coming back. It would have been just my luck for it to come back, because not only did I have severe haemophilia and had contracted HCV, I had contracted the worse type of HCV, which is the hardest to get rid of. Fortunately, the HCV has never come back and I have been clear from the virus since 2003.

46. Around the same time that I cleared the HCV, following my third course of treatment, I received a letter informing me that I had been given blood products from a donor who had then later developed Variant Creutzfeldt-Jakob Disease ('vCJD'). It completely knocked me back down. I was devastated. It couldn't have come at a worse time, it arrived without any warning and it was right at the end of my treatment. This made me really angry and sent me into a deep depression. I went and complained to the Haemophilia Centre. I said, "Why didn't you tell me that the letter was going to come? You knew I was going to receive it and that I had just cleared the treatment. You knew I was suffering with depression. Why couldn't you bring me in for a chat and explain it to me and tell me there wasn't anything to worry about?"

47. This was the same time that on the news there were videos of cows having wobbly legs and falling over before dying. I became terrified

because I knew that if I developed vCJD, I would die within in a few months. This fear has never properly gone away and I have periods of my life where I will spend weeks constantly worrying about developing vCJD. I can forget it about it for a few weeks sometimes but the thoughts always come back. When I think about the vCJD, I worry that I might die younger than I should, that I might miss out on parts of life and miss out on seeing my nieces and nephews grow up. I feel like I have been through enough with the haemophilia and the HCV and I can't believe that I now have to deal with the vCJD.

48. Soon after learning about being exposed to vCJD, I began having suicidal thoughts again. I was feeling very low. I thought what is the point of living. I didn't believe the hospital when they said that the chances of developing it were low. I also couldn't believe, knowing what I had been through, how flippant they were about the possibility of me developing vCJD. When I was at the Haemophilia Centre I said, "this is what I believe, not what you're saying." They got someone else at the hospital to come and try and convince me I would be ok but I thought they were trying to cover it up and were just telling me that I would be ok because they knew I was depressed.

49. I would be sitting with my legs crossed, they would shake and I would think this is the start of vCJD. I began thinking that if I was going to spend my final few months dying of vCJD, what is the point in living? These thoughts continued to build up and I began planning to commit suicide. I called my aunt in America, who I don't speak to very often. I wanted to call her and apologise for being horrible to her. I didn't want to die without making my peace with her.

50. I researched that if I jumped into a specific part of the River Severn and timed it right, I would die on impact, my body would be taken out to sea and no one would ever find me. My grandma, with whom I was very close, had died by this point and I didn't tell anyone about what I was planning to do. I got in my car and headed towards Wales, to the

location where I intended to commit suicide. When I set off on that journey I knew exactly what I was going to do.

51. I got onto the motorway and I got stuck in traffic. I think there was accident or something had happened on the motorway because I was stationary for ages. I am not sure what happened next but something happened to me. I thought, "Why am I doing this to the people I love? I won't be around anymore; I'm going to be dead and everyone around me is going to suffer." I seemed to change, it was strange, it was like a trigger, depression turned into anger and I thought, "Why am I doing this? Why am I letting them win? It is like I have received this letter and now I am giving up." I don't know what happened but something triggered in my mind. I told myself, "don't give in and let that beat you, you've been through so much, you've just lost your grandma and just cleared HCV so don't let this beat you." When I had the opportunity I turned back, making a conscious decision not to carry it through.

52. I got out of this period of depression through counselling, provided by the Met which began with six counselling sessions a week. I am grateful to my counsellor for helping me get through this difficult time but there have since been other periods when I have struggled to cope with what has happened to me and it has severely affected my mental health.

53. In 2012, I had another significant mental episode. I split up with my girlfriend and this triggered a long period of depression. This was just before Christmas in 2012 and I was told by the hospital that I should not be by myself. So I began sofa-surfing to make sure that I was constantly with people. My friends were so supportive and helped me so much. A few of them knew why I was doing it and I felt like I could cry in front of them. Others just let me stay but we didn't discuss it. Work were brilliant with me once again during this phase. My line managers were so supportive and they would allow me to take time off when I needed it.

54. The support from my friends and my colleagues has helped me get through difficult periods. People always seemed to really want me to get better and that is so humbling. Every year I write to my line manager's line manager and the Commissioner, currently Cressida Dick, to let them know how much I appreciate everything they do and have done for me. I have healthcare needs throughout the year and I really couldn't ask for more support. I recently wrote to Commissioner Cressida Dick to say, "The Met gets a bad reputation, but I've been here for 29 years and thanks to the support and help that I get through occupational health and my colleagues, I am still here today." After a few days I got a reply from her. She told me how proud everyone was of me and that I was an example to people working at The Met.

55. I still have mental health issues but I try to have a different attitude to the vCJD. I try to tell myself that any day I spend in the house sitting around getting angry or depressed about developing vCJD is a day that I will never get back, so what is the point? I try to convince myself to think, if it happens, it happens and there is no point worrying about it.

56. I feel like I have retained some of the negative aspects of the HCV treatment. For example, even now, I find myself being snappy with people I love. I like to think that isn't my natural personality and hopefully it isn't a result of having vCJD either. It is hard to not beat yourself up about things like that. Some days, I find it difficult to not blame myself and think positively. I try to remember that I still have a lot to live for and I still have the people I love, but it isn't easy. I know that if I didn't get the support and counselling that I get through The Met, I would not be here now.

57. I have had to visit sudden deaths and suicides as part of my job. However, it is strange that whenever I visit someone who has killed themself, I never think, "oh that could have been me". For some reason, I don't associate it with my own troubles and my own suicidal

thoughts. I can't say that my job and these experiences haven't affected me at all, I have seen a lot of horrible things, but I like to think that these are separate from my own experiences. I believe that I am able to compartmentalise my job from my private life.

58. Nowadays, if I feel like if I am having a particularly bad time mentally, it will be because vCJD or infected blood has been mentioned in the press in some way, most recently to do with the Inquiry. For example this article in the Daily Mail on 19th May 2019 made me so angry **[WITN0954002]**. If I read about someone who has been infected or one of their relatives, it makes me very angry. I went through a particularly dark period recently when I visited the Haemophilia Centre and four people who I had joined the centre with had died as a result of infected blood. This made me so angry and I felt very low after that. I sometimes feel exhausted from being angry, so I try to limit my anger or at least not let it show.

59. In 2018, I was fortunate to be offered gene therapy for my haemophilia. It had been trialled in the United States and the researchers wanted to try it on patients in the UK. On 4th September 2018, I was infused with a gene inside a virus and I began a six-month course of steroids to stop my liver swelling. I began making Factor VIII from that date and I have not taken any recombinant or blood products since then. I have even had an accident since then when a rock hit me on the head and I began bleeding. I panicked but all of a sudden it stopped bleeding. I went away and cried. It has changed my life and is an exciting prospect for young haemophiliacs, who ultimately will not physically suffer in the same way of those, like me that have gone before them.

60. To be honest, although this was brilliant for me physically, mentally it turned me upside down because I found it very difficult to process the fact that the haemophilia that I had suffered with for 50 years was suddenly gone. This gene therapy had to be tested on someone and I

am proud to have been able to give something back and to be one of the first people to get this treatment.

61. Last year, I was interviewed by a French newspaper, L'Express, about my gene therapy treatment. The Haemophilia Centre had asked me to go on TV to talk about it but I didn't think it would be appropriate. My Factor VIII level had gone up to 72% clotting factor, it now averages at 46%. The 'normal' range of a non- haemophiliac is between 50 and 150%. I don't really understand how it can be 150% though it has been explained to me. Therefore I am at the lower end of 'normal'. This means that I no longer get spontaneous bleeds like I used to. In many ways, the treatment has changed my life. I love going fishing and I no longer get ankle bleeds while fishing. Another example is that I can now go abroad and travel without needing to take Factor VIII or worry if I have enough of it. It is difficult to appreciate having these seemingly 'normal' things, until you have lived for so long without them.

62. I have been asked if I would like to give further details of the impact HCV has had on my life. After I learnt that I contracted the HCV from Factor VIII, I still had to regularly self-administer. I didn't want to inject myself anymore. I would hope that the bleeds would go away. I would put the needle into my arm and wonder what virus was in the blood product I was giving myself. I now have bad ankles because of hesitating over whether to inject myself when I had a bleed. I only stopped feeling this way about self-administering when I moved onto recombinant.

63. I am 54 and I have never been married or engaged. I have been in a number of relationships and I have always thought I would be a great husband and father. I would love to have had a son to take fishing. The reason I have never been married is that I have always been worried that I would get close to someone, we would get married and I would die. I have never been able to stop thinking that I wouldn't want

someone that I love to go through that. It has forced me to keep my distance.

64. It is painful to even think about this. I have only just started talking about this to my counsellor. I have never told any of my partners that I feel this way. I have never given anyone the opportunity to talk about it with me or make me feel differently. I regret not having spoke about it earlier in my life. I would say this is, without the shadow of a doubt, the biggest impact the HCV has had on my life. It is fairly normal to have a partner and start a family. People say to me, "you would be a really good dad" but I have now accepted that it is never going to happen.

65. The impact the HCV has had on my parents hurts me. I insulated my parents from what was happening to me, I couldn't tell them how bad I felt. I felt like I was a burden to my family and those around me because of my haemophilia. The HCV made this much worse, as did my depression. I am a burden and I have been a burden for a long while. As I have said, I have felt like that since I was child, I still feel like that now and I feel like a burden at work. No one would admit it to me because they are too supportive but I know that people have been 'carrying' me.

66. **GRO-C**

GRO-C I can remember them having arguments and often it was about me going to hospital for haemophilia treatment.

67. GRO-C

GRO-C This is why I feel guilty and I have always felt like a burden. I think for a lot of my life, I didn't acknowledge these feelings. It is only since I have had counselling that I have been able to talk about this.

68. Despite everything I have said, I am aware of other people who have been infected with HCV through contaminated blood and I think, in some ways, I have been lucky in terms of the impact the HCV has had on my life. I haven't been as ill as some people and I cleared the infection before I got cirrhosis or liver cancer. I have also been fortunate in that I have been able to work for most of my life. And I have had a very satisfying and worthwhile career.

Section 6. Treatment/Care/Support

69. I am very happy with the treatment that I have received from Professor Christine Lee and the staff at the Haemophilia Centre at the Royal Free Hospital. Professor Lee used to see me for reviews every six months and sometimes more frequently. I can remember her asking how much alcohol I drank when I was about 18. Around that time, I had started going out with friends. She said, "Paul, I'm advising you not to drink because you have hepatitis." She explained that because I didn't have a healthy liver, the liver wouldn't be able to regenerate the cells. From then, it felt like every time I had a drink I was losing a bit of my liver that I would never get back.

70. I felt confident talking to Professor Lee because I felt that she did her best to help me. I could always go to her with health problems, whether or not they were related to my haemophilia. Professor Lee's husband was a consultant at the Royal Free Hospital, so if ever I needed to see anyone for reasons unrelated to my haemophilia, either Professor Lee

or her husband would organise for me to see the best people. For example, if I went to her and I was suffering with headaches, she would ensure that I see a specialist or have the required tests as quickly as possible. In this way, I always had fantastic treatment from the Haemophilia Centre; it felt like they did more than they needed to. I was even one of the first people to be given recombinant because of the impact of learning that I may have been exposed to vCJD had on my mental health.

71. When I realised I contracted HCV through infected blood products, to stop myself getting really angry about it, I would tell myself: "This has actually kept me alive, so what were my other options?" I always assumed that the Haemophilia Centre never knew the blood products were infected. I think I never considered that they might have known the Factor VIII was infected until a few years ago. I thought they couldn't have known because of the amazing care I received. After a period of reading more and more about the infected blood scandal, I was at a Haemophilia Centre and I decided to ask the nurse if they knew. I said, "Did you know you were giving me infected blood?" The nurse told me that it was possible to track the batches of Factor VIII that I received to say whether they were infected but my question was never answered satisfactorily. I didn't push it.

72. As I have said previously, I have received counselling through my job with The Met. The focus of the sessions has been on me feeling like a burden and feeling guilty for what I have put people through. I know that I have made people's lives more difficult and sometimes that is hard to live with. I cannot thank my counsellors enough because they have saved my life.

73. I was never offered counselling on the NHS. I feel that the treatment for mental health problems on the NHS is poor. I think that I would have had to push really hard to get any treatment and I am very lucky that I

was able to get help through my work. Others would be less fortunate I guess. I would tell the doctors at the Haemophilia Centre that I felt depressed and they seemed to treat me as if it was less important because the Interferon had made me predisposed to depression. I feel like they should have listened to me more, especially around the time that I received the letter informing me that I had been exposed to vCJD. I tried to explain to them that it was their fault that I felt the way I did. They should never have sent me that letter.

74. I have never faced difficulties accessing dental treatment. However, I had to be treated at the Royal Free Hospital until I cleared the HCV. Once it was cleared, the Royal Free Hospital sent a letter to my local dentist and from then on, he provided my dental treatment from 2010/11.

Section 7. Financial Assistance

75. I can't remember how I became aware of the Skipton Fund but I applied for financial assistance and was successful, I received an initial payment of £20,000 and £500 pounds cold weather payment I December every year. In 2017, my financial assistance was transferred to the English Infected Blood Support Scheme (EIBSS). I am currently on the higher rate of payments, which is £2,300 per month and a £500 cold weather payment. This was increased to the current rate when Theresa May decided to review the scheme and increase the payments, after the Infected Blood Inquiry started. This has enabled me to reduce my hours at work and will therefore allow me to work for longer. I do still frequently feel very fatigued.

76. I was previously on Disability Living Allowance but I was removed from the scheme when it changed to Personal Independent Payments ('PIP'). I was told that I did not meet the criteria of not being able to walk 20 metres unaided, on the day of my assessment.

77. A few months later, I was at the Haemophilia Centre and I saw a leaflet, which said all PIP cases involving haemophiliacs were being reviewed and in cases where a claimant had haemophilia arthropothy, the benefit could be reinstated upon review. I phone the Department of Work and Pensions to ask why my case had not yet been reviewed. I was asked to send in a letter from the Haemophilia Centre. I did so and then payments were subsequently reinstated.

Section 8. Other Issues

78. I want to thank the Inquiry for taking my statement and for recording my story as part of this process. I feel better for having done the statement. It means a lot to me that something is finally being done. I never thought I would live to see the day that this Inquiry would actually be happening. I have always wanted to go up to Sir Brian and shake his hand and say thank you for fighting for this.

79. I want someone to be held fully accountable. Compensation is fantastic but I want someone to stand up and acknowledge their responsibility for what has happened. I want them to mean it and I want someone to call it 'culpability'. It wouldn't make me feel better seeing people in prison but I would like them to admit what they've done wrong and that they have covered it up.

Statement of Truth

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

Signe GRO-C

Dated 3RD MARCH 2020