Witness Name: Mr. P A Hayes
Statement No: WITN1750001
Exhibits:WITN1750002/6
Dated 9th August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PHILLIP ANTHONY HAYES

I, Phillip Anthony Hayes will say as follows:-

Section 1. Introduction

1. My name is Phillip Anthony Hayes. I was born on the GRO-C 1972 and live at GRO-C with my wife and three children. I am a self employed web developer/ programmer and work from home.

2. I was infected with Hepatitis C genotype 1B (HCV) as a result of being given infected blood products.

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

Section 2. How infected

4. I suffer from Haemophilia A classed as mild. I was diagnosed when I was about 4 at Sheffield's Children's Hospital, Sheffield (SCH) after a circumcision operation carried out at Doncaster Royal Infirmary, Doncaster

(DRI) as I wouldn't stop bleeding. As an emergency I received BPL Factor VIII at SCH.

5. Although my records show that I should have been tested at the age of 18 months due to my family history of Haemophilia and there was a warning about bleeding from any surgical procedures (like circumcision) being attempted, the DRI ignored this information. I refer to exhibit WITN1750002.

6. Over the years, I have been mostly treated with Cryoprecipitate. I have attended the (DRI) for general issues from 1972 to the present day. Between the years 1976-1989, I attended SCH, under the care of Dr Lilleyman and Dr Wodzinski. From 1989 to the present day, I have also been treated at Sheffield Royal Hallamshire Hospital, Sheffield (SRH) under the care of Dr. Preston, Dr. Makris and Dr. Hampton. I attend the Charles Clifford Dental Hospital, Sheffield(CCD) for any dental extractions.

7. In 1981, I received commercial Factor VIII , at SCH Hospital in preparation for a tooth extraction at CCD. Different documents and records state contradictory information about what blood product I was treated with. The Episode Summary obtained from my GP, states that I received Tranexamic acid and Cryoprecipitate for this, however in the History Sheet referral letter dated February 1989 from SCH to the SRH it says that I had the tooth extractions under Factor VIII cover. In the Clinical notes from the SRH my infectivity with HCV is put down to the BPL Factor VIII I received at the age of 4 (1977) I refer to Exhibit WITN1750003.

8. In 2004/2005, when the possibility of infection with vCJD was considered, my consultant stated in two letters, that I had received Factor VIII in 1981 and that it wasn't a UK NHS product, (therefore implying it was commercial Factor VIII.) I refer to exhibit WITN1750004. I recently found out that he encountered great difficulty in obtaining this information. I don't know where he was able to obtain this information from as I had been told that my medical records from SCH had been destroyed when I reached the

age of 25.Strangely my Haemophilia data base treatment record shows all my treatments except for the year 1981. I refer to Exhibit WITN1750005.

9. Until I went to the Infectious and Tropical Diseases Department at SRH for treatment for my HCV infectivity in 2015, I had never been aware that I had received Factor VIII in 1981. Up to that point, I always thought I had been infected with HCV as a result of the Factor VIII I received at the age of 4, as this was what I had been told by the medical staff.

10. Neither my parents nor my grandparents were told beforehand there were any risks of me being exposed to infection from blood products. Later on, I became aware from the media of the risks of HIV. I remember being very scared of receiving blood products but the nurse at the SCH reassured me that they were heat- treated and therefore safe.

11. Although I cannot be entirely sure, I think it was Dr. Makris at the SRH in or about 1998, who told me I was infected with the HCV virus. I was given some leaflets. From what I can now recollect, I was told that I needed to use protection during intimate relationships, and be careful when cleaning up blood, so as to protect others from becoming infected. He also explained that in 20% (or it could have been 10%) of cases, patients could develop liver cancer, In another 20% (again it could have been 10 %) they would clear the virus and in the majority of cases (60-80%), patients were able to live with the virus without it affecting their lives or suffering any major symptoms.

12. I remember feeling relieved that it wasn't HIV (something that had played on my mind because of the blood products I had received).The doctor seemed to be saying that the majority of the infected people were able to live normal and fulfilled lives. The severity of the HCV was downplayed, so I wasn't too concerned. I took the leaflets and I don't think I actually looked at them properly as HCV didn't seem life threatening at that moment in time.

13. Later on, in 2000, during my first serious relationship I looked HCV up online and the seriousness of my condition together with the stigma truly hit me. I was terrified.

14. I now know that they were testing my liver functions, also for HIV and Hepatitis long before I was told. I refer to pages 4/5 of Exhibit WITN1750003. In my medical records, I found test results that confirm I was HCV positive in September 1993. In 1994, my SCH History sheet was updated to include HCV. On a blood test result from 1996, the words "past Hepatitis A infection" appear. I refer to Exhibit WITN1750006.

15. If I would have been told about the seriousness of my condition in 1993 and had the issues been properly explained, I might have made different life choices. I am lucky that my condition did not drastically worsen in the meantime. But that is exactly what it is...LUCK.

16. The information about my infection was not adequate and the seriousness was completely downplayed. I believe that I should have been told of my infection when I first tested positive.

Section 3. Other Infections

17. I do not believe I have received any other infections other than HCV, however I can not say with any certainty that I am correct in this belief.

Section 4. Consent

18. The Episode Summary concerning the tooth extraction in 1981 says that I received pre-operative Cryoprecipitate, which is the treatment I normally received when I had a bleed. My bleeds were rare due to the fact that I am a mild Haemophiliac. The later correspondence/documents contradict this and state that I received Non UK Factor VIII on that particular occasion. This conflicting information is alarming and suggests the very likely

possibility of myself having been tested or treated for the purpose of research without my knowledge or consent.

Section 5. Impact of the Infection

19. During my childhood and adolescence I had a lot of time off school due to illness. I remember having a bad rash that doctors couldn't diagnose. Throughout my life I have struggled with tiredness (I used to be called lethargic), severe headaches, pain in my abdomen and chest, brain fog being unable to concentrate for long period of times, rashes, bowel and digestion problems coupled with anxiety, breathlessness and more recently an intolerance to alcohol (I only drink an occasional beer).

20. For many years, I refused to be treated with Interferon and Ribavirin as I had seen with my own eyes how this treatment had affected my uncle (who was also a Haemophiliac) and who had been infected with HCV just like me. He suffered serious side effects while on the above treatment and eventually was forced to discontinue it. He died in 2008 from liver cancer. I truly believe that the Interferon/Ribavirin treatment did more damage than the HCV.

21. As I have stated above, I refused the combined treatment as I was worried it would affect my health and also render me unable to work (and result in me losing my job). In or about 2016, when Harvoni came out, I asked my Haematologist about it and he referred me to the Infectious and Tropical Diseases Department of the SRH, where I was again offered the combination treatment that I had previously refused. I asked for Harvoni and explained my reasons behind my choice. I had researched Harvoni prior to this meeting. I was due to start on Harvoni at the following appointment, but when I got there it wasn't available and they offered me the combined treatment instead yet again. They explained that Harvoni was being prioritised depending on the severity of the condition. I asked what other criteria there was and once I had told them I had a young

family and what my liver scans were, they agreed to put my case forward at the next review meeting.

22. I was given another appointment to start treatment with Harvoni. Yet when I went to the appointment I was told again that it had not been approved for me. I was constantly being let down and having to make arrangements (work, travel) to get to these appointments in Sheffield from Doncaster where I was living. I was very disappointed. A few days later, I received a phone call, asking me if I was able to commence treatment the following week as a cancellation had occurred and they had a course of Harvoni available. I didn't have time to make preparations, but I took the offer and now I am virus free.

23. While undergoing the Harvoni treatment, I suffered with almost constant headaches and occasional breathlessness. My ability to concentrate on work severely diminished. I was fatigued and this symptom has progressively worsened. I also suffered (and still do) with anxiety in relation to the treatment and its repercussions.

24. Whenever I needed a blood test, the forms had a large bio hazard sticker on them. I was so afraid of the other patients seeing it, that I used to fold the forms and cup them in my hand. Another incident that I can recall was during a dental x-ray, when the nurse simply pointed towards the bin for me to dispose of the gauzes. Other than that, I can't remember any other issues.

25. Due to the stigma attached to HCV I never told anyone about my infectivity other than close family members, parents, grandparents and uncles. I am still concerned that people will find out. I am especially worried for my children. As a result, I have been rather withdrawn and I avoid most social interactions. Only recently (since the Inquiry has started) have I felt comfortable enough to discuss my situation with my best friend.

26. I had two serious relationships and both times I had felt incredibly anxious when talking about my HCV. I had to prepare myself, build my confidence up, in order to be able to tell them about my infectivity. I remember being absolutely terrified both times.

27. Whenever I cut myself, I panicked, not allowing anyone to come near me or my wound. Though the chances of my wife becoming infected were very small, when she was tested I was still worried.

28. Having three children is demanding and I feel that I am not able to do all the things a father should do. Going out for an extended period of time (more than a couple of hours) is a strain physically and mentally; I end up with a headache and fatigue (which extends to the following days). Playing with the children leaves me breathless and exhausted.

29. I hid my condition from my employers and colleagues as I was afraid I would lose my job and with no available life insurance, I had to make sure my family was financially secure. Unfortunately, due to increased fatigue and stress, I had to resign from my full time job and become self-employed, working from home. This suits me better, as I can rest when I feel that the tiredness and lack of concentration overwhelms me. Of course this is not ideal as we do not have financial security.

30. I have kept my infectivity with HCV a secret due to the associated stigma. So did my family (parents, grandparents). I recently became aware of the fact that some family members feel ashamed of my uncle's infectivity and subsequent death. They prefer telling people that he developed liver cancer due to heavy drinking, a fact which isn't true. As I mentioned before, my uncle, a Haemophiliac, was infected with HCV from contaminated blood products he had received. His liver cancer was the result of that.

31. Both the schools I attended (primary and secondary) were aware of my Haemophilia and I wasn't allowed to participate in any physical activity or

certain school trips. Though my Haemophilia was mild, it appeared to me that they didn't fully understand my condition and therefore I missed out on a lot of things that all the other children were doing. At the age of 9, I received contaminated Factor VIII. The following school years were plagued by illness. On one occasion (around the age of 12), I developed a severe rash that doctors couldn't diagnose or treat. I ended up having nearly 3 months off school. Throughout my years at the secondary school, I had a tremendous amount of time off. On one school report, I remember the percentage for attendance being of only 45%. Because I missed all my academic assessment exams, I was placed in remedial classes for many of my subjects. Due to my illness related absences, I was not allowed to sit my maths GCSE (I did eventually take the exam while at Art College and passed). During Art College, my academic achievement improved.

32. I started work at the age of 23. When I was about 29, I began to feel increasingly tired while at work and sometimes even struggling to stay awake. Progressively, the fatigue and severe headaches became overwhelming. Several times, I have had to have unpaid time off work. I felt unable to carry on like that, and at the age of 39, I made the decision to resign from my full time job as a web developer and become self employed working from home. Luckily, I had the opportunity to find some work in the same area. Working from home allowed me to take breaks and rest whenever I needed. Even though, I am now virus free the above symptoms haven't improved. If anything they have worsened. At the present time, I am only able to work 2 to 3 hours, after which I need to lie down and have a rest or a nap. If I need to attend any meetings, I struggle to stay awake and fully concentrate even before the lunch break. I end up with a headache and on my return home I need to go to sleep propped up. I carry with me headache tablets no matter where I go. It simply feels as if I had done a 12 hour shift. I find it disheartening looking around the meeting table and noticing how alert and focused everyone else is.

33. I have never been money orientated, but I have to admit that at times, (even while I was in full time employment) due to having to take unpaid sickness leave things have been a bit tight. I ended up having a considerable amount of debt, most of which I managed to pay off, when I received the ex-gratia lump sum payment of £20,000 from the Skipton Fund. In the past, my grandparents ended up helping us financially numerous times.

34. It is mainly my fatigue that has limited the things I can do in my everyday life, especially with my family. A day out is a real struggle for me. The few times we went on holidays, I would need to return to the hotel for an afternoon sleep, which made it difficult and frustrating for all of us. This also happens at home and it mainly falls onto my wife to take the children out to the park, into town, activities, parties, school trips. I feel that because of my condition, my wife has to do more than her fair share, compensating for all the things I can't do. My wife told me, that for her and other family members, the main impact of my being infected with HCV has been and still is the constant worry and anxiety surrounding my wellbeing.

Section 6. Treatment/care/support

35. The interferon and Ribavirin were always on the table for me. But when the new Harvoni treatment came out, I had problems obtaining it. Harvoni should have been made available right from the beginning, Instead I had to live through an emotional rollercoaster. After the treatment had finished and the results came back clear, I was discharged. I asked for another liver scan, but was refused. Every time I go to see my haematologist, I mention the liver scan. I am told that they can only refer me, but that it is down to the Hepatology department to decide. Up to this day, I haven't been offered another liver scan. I do get occasional pain and I am worried something might be wrong. I brought this issue up yet again during my "over the phone" appointment in July this year. Normally, I would have a yearly medical appointment, whereby I would have all my checks done, including blood tests. These have now moved to once a year telephone

calls. The Haemophilia Centre at SRH suggested that this is for my own comfort, as it spares me travelling to Sheffield (I live in GRO-C). The arrangement, set last year, consisted of chatting to a nurse over the phone and then they would arrange for me to have any blood tests done at my local GP. Unfortunately, I found the actual phone call rather disappointing and disturbing. The nurse who rang me enquired about my family's haemophilia history, including very distant relatives. She asked for their names and surnames, even the correct spelling of their names. I do not consider this to be of any relevance to my appointment. When I asked her why they needed that information, I was told that it would go on my file and that they would send me a new Haemophilia card, which in the meantime I have received. I think that the nurse realised that I was unhappy with how the appointment went, so she asked me if I would prefer to go back to yearly face-to-face meetings. Of course, I agreed. I was also advised to check our daughters, as to whether they are Haemophilia carriers. Once again, I asked to have a liver scan and explained my concerns. The nurse said that she will try to arrange it and let me know about the outcome by the end of the week. I still have not heard anything back after 2 weeks. It feels to me like the Haemophilia Centres are starting to distance themselves now, that I had my treatment and am HCV free.

36. Only two years ago, I was offered counselling while attending a meeting at the Haemophilia department at the SRH. I politely declined. This is not adequate for the impact it has had on my life and my family. Counselling and or psychological support should have been offered to me and also to my wife a long time ago.

Section 7. Financial Assistance

37. I found out about the Skipton Fund from my uncle (a haemophiliac infected with HCV). I can't remember the exact year (maybe around 2005). While I was researching Harvoni (around 2014), I came across a post by the Tainted Blood group that contained information about the Caxton Foundation. A few years later, I received a letter from EIBSS informing me of the change from the old schemes to the new NHS run scheme. The

nurse from the Haemophilia department at SRH helped me fill in the SCM forms.

38. I received £20,000 from the Skipton Trust for stage 1 HCV, in or about 2005 for which I had to sign a waiver agreeing not to claim for any other infections in the future. In addition, I received from the Caxton Foundation £350 in 2014 as winter fuel payment, that then increased to an yearly payment of £500 (that increases with inflation each year) and from 2015 a payment of £291.67 monthly income to-up and from 2017 £250 monthly.

39. Under the new scheme, I received from EIBSS £1,500 monthly, with an income top up of £695. These two monthly payments have now changed to £450 child supplement and £2333 stage 1 and SCM.

40. I have never applied for any grants or emergency funds, due to the complicated and drawn out application process. In contrast to the other schemes for ex-gratia payments, the EIBSS require a lot of paperwork and documents. I found the whole process overly complicated.

41. Only on a couple of occasions, have queries been raised by the EIBSS. Other than those occasions, I have been lucky enough not to have encountered any significant problems.

42. Having been infected with HCV, I haven't received any on going financial assistance until quite recently. As a result, I ended up in substantial debt and had to use the payment from the Skipton Fund to pay most of it off. If it wouldn't have been for my uncle telling me about the Skipton Fund, I would have ended up in a disastrous financial situation.

Section 8. Other Issues

I have nothing further to add.

Anonymity, disclosure and redaction

42 I do not wish to be anonymous and do not want to give oral evidence

Statement of Truth

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

Signed....GRO-C...

Dated.....09/08/2019.....