Witness Name: Mrs. M O Hayes
Statement No: WITN3582001
Exhibit: 0
Dated: 9th August 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF MONICA OANA HAYES

I, Monica Oana Hayes will say as follows:-

Section 1. Introduction

1. My name is Monica Oana Hayes. I was born on the GRO-C 1979 and live at GRO-C with my husband and our three children. I am a self-employed teacher and translator, and work from home.

2. This statement is made in relation to my husband Phillip Anthony Hayes (Phillip), who was infected with Hepatitis C genotype 1B (HCV), as a result of receiving contaminated blood products.

3. Phillip has provided a Witness Statement to the Inquiry(WITN1750001) and all references to Exhibits in this Statement are to the Exhibits in his Statement.

4. This witness statement has been prepared without the benefit of access to Phillip's full medical records.

Section 2. How affected

5. Phillip suffers with Haemophilia A classed as mild. He was diagnosed at Sheffield Children's Hospital, Sheffield (SCH), when he was 4 years old as he bled profusely after a surgical procedure (circumcision) at the Doncaster Royal Infirmary, Doncaster (DRI), and was subsequently treated as an emergency with BPL Factor VIII at SCH.

6. His medical records (Exhibit WITN1750001) show that he should have been tested at the age of 18 months, due to his medical family history and that any surgical procedures (including circumcision) should not be attempted without careful preparation. Unfortunately, the DRI ignored this and only when they simply could not stop the severe haemorrhage, they transferred him in an ambulance to SCH, where he was diagnosed with Haemophilia and treated with BPL Factor VIII.

7. I refer to paragraphs 6 to 9 of Phillip's Statement which detail the hospitals where he has been treated, the treatment received and the inconsistences in his medical records as to which blood product he has been treated with.

8. Phillip has told me that he believes that he was informed in 1998 about his HCV infection at the Sheffield Royal Hallamshire Hospital, Sheffield (SRH), when he was 26 years old. He cannot remember exactly which consultant it was, but he thinks it was most likely Dr Makris. When Phillip told me about it, he said that he was relieved that it was not HIV, something that had played on his mind for a long time.

9. Phillip has also said that, when he was told about his HCV infection, he was told to be careful, to use protection during intimate relationships, to be cautious when cleaning up any blood spillages in order to protect others from becoming infected and he was also given some leaflets.

10. I met Phillip in April 2003 and we married in October of the same year; since then I have accompanied Phillip to almost all of his appointments at the Haemophilia Clinic at the SRH. We were told that the chances of him infecting me were extremely low and when I became pregnant with our first child, I was tested just for reassurance. Thankfully, my test results came back negative.

11. It is difficult to say exactly when Phillip was infected, as we have come across contrasting information. In the History sheets from the Royal Hallamshire Hospital, Phillip's infection with HCV was put down to the BPL Factor VIII that he had received at the age of 4 (1977) Exhibit (WITN1750003), even though in the referral letter from SCH to SRH it is stated that he had received Factor VIII also in 1981. Yet, the Episode Summary for the tooth extraction from 1981 obtained from the GP states that Phillip had been given Tranexamic Acid and Cryoprecipitate. Exhibit (WITN17500003) Later on, in 2004-2005, when the possibility of infection with vCJD was considered, his consultant stated in two letters that Phillip received Factor VIII in 1981 and it was not a UK-derived product, implying that it was a commercial Factor VIII Exhibit (WITN1750004).

12. We recently found out that the Consultant encountered great difficulties in obtaining this information. We do not know where he eventually obtained the information from, as we were told that Phillip's medical records had been destroyed when he turned 25. The Haemophilia Database records all his treatments, except for 1981 Exhibit (WITN1750005).

13. When we went to the Infectious and Tropical Diseases Department at Royal Hallamshire Hospital for his HCV treatment in 2015, we were told for the first time that he had received commercial Factor VIII in 1981. Until then, everyone (including himself, due to the information he had been given by the medical staff) attributed his infection to the BPL Factor VIII he had received in 1977.

14. I have my suspicions about the exact time the doctors knew about Phillip's infection. The test done in 1993 came back HCV positive, but he was not told

about it until 1998. He should have been told in 1993, the moment the positive results were registered. His liver functions were being tested since childhood. The doctors clearly questioned the possibility of liver disease or at least liver damage. I do not understand why he was not made aware of this before.

15. Considering the seriousness of the matter, I do not feel that informing Phillip was handled appropriately and also the information given to him did not stress the severity or consequences of HCV.

16. I have asked Phillip's family (parents and grandparents) about them ever being informed beforehand about the risks of being exposed to infection from blood products. None of them recall ever being told anything about the risks involved.

Section 3. Other Infections

17. We are not aware of Phillip contracting any other infections, as a result of being treated with contaminated blood products.

Section 4. Consent

18. I refer to paragraph 18 of Phillip's statement and adopt and agree with it.

19. I would add that considering all the discrepancies in Phillip's medical notes and after studying all the available documents, I consider there is a strong possibility that Phillip might have been part of medical research involving commercial Factor VIII. Phillip fitted the required subject profile from the commercial Factor VIII point of view, as he was "a virgin haemophiliac".

Section 5. Impact

20. Phillip's infection still causes us great anxiety. I remember clearly the day when he told me about being HCV positive. The trembling voice, the nervousness, the fear. He said "I need to tell you something" and then, during a pause that felt like an eternity, my mind was left to imagine the most horrific scenarios. Once he told me about the HCV, I must admit that I was somehow relieved. In the moment, I imagined something far worse, but also HCV was something I knew a fair amount about. I had a close friend who was infected with the same virus. HCV was not going to stop me from loving Phillip and wanting to spend my entire life by his side.

21. Phillip has always been careful. At the beginning he did not allow me anywhere near his cuts or grazes, but after reassuring him that I knew how to protect myself, he finally allowed me to safely clean and treat any minor wounds. I knew he was afraid of infecting me and I remember how worried he was when I was being tested for HCV.

22. After his uncle passed away due to HCV, Phillip's anxiety about his infection and its outcome grew larger. A year later, my father died from HCV and HBV (Hepatitis B). We all worry about our mortality, but in Phillip's case it is a shadow that follows him around continuously.

23. The most obvious physical effect of HCV on Phillip was and still is severe fatigue. There were times when he was struggling to stay awake and concentrate. It affected his job and our private life.

24. Phillip was originally offered Interferon and Ribavirin combined treatment, but he refused it because he was worried that it would affect his health and also render him unable to work. He saw how the treatment affected his uncle when he was being treated and even to this day he strongly believes that this was more likely to be the cause of his uncle's death than the virus itself.

25. Once Harvoni came out, we asked the Haematologist about it and he referred Phillip to the Infectious and Tropical Diseases Department at the SRH.~~,~~ Strangely, he was offered another combined treatment there, which he politely refused. We researched Harvoni and we were convinced that this was the best treatment for him.

26. He was due to start on Harvoni at the following appointment, but when he got there he was told that it was not available and they offered him the combined treatment yet again. They explained that Harvoni was being prioritised depending on the severity of the condition. Phillip insisted on receiving Harvoni~~,~~ and he was given another appointment. He went and was told it had not been approved once more. We were so disappointed and angry. It was disheartening. A few days later, we received a phone call, asking if Phillip would be able to commence treatment the following week, as someone cancelled their treatment, so there was a course of Harvoni available. We had no time for preparations, but it was a chance we could not miss.

27. Phillip started his treatment around May/June 2016 and it lasted for 8 weeks. Thankfully it proved to be successful and Phillip cleared the HCV with no major complications. However, he suffered from headaches and fatigue. He was constantly tired, then the fatigue went away for a period of time, but unfortunately it came back in the last week of treatment. It seems like it has been getting worse post-treatment, and he still suffers from it to this day. It is now a lot worse than it was pre-treatment.

28. Some other side-effects of his treatment included occasional breathlessness and inability to concentrate at work. He also suffered with anxiety.

29. I recall that Phillip was always rather lethargic, or at least since I met him, however, it has become even worse since the Harvoni treatment.

30. I strongly believe that Harvoni should have been made available right from the beginning. Instead, we had to live through an emotional rollercoaster: building up hope only for it to be destroyed. Putting aside this aspect, I am grateful that Phillip was able to finally receive Harvoni and is now HCV free.

31. Unfortunately, the doctors at the SRH did not think a liver scan would be necessary. We have been asking for one, but were refused. This is causing us great concerns. The last scan Phillip had was before his treatment, and since then we have repeatedly asked for a liver scan, however, with no success. Their reason for no scans is that there is nothing to see. The haematologist requested tests, but they have been refused by the Hepatology Department of the DRI.

32. We are aware that other patients are still being checked even long after they cleared HCV. A liver scan and regular check-ups should be made available to Phillip, even if it is only for our peace of mind. Research shows that Harvoni appears to speed up the progression of liver cancer.

33. Due to the stigma attached to HCV, very few people knew about Phillip's infection. Only close family members (parents, grandparents and uncles) were aware of it. He only told his best friend very recently. He was always afraid that informing people about it could result in stigma, so he was especially worried about our children. As a result of this, he became rather withdrawn and he avoided most social interactions.

34. Phillip kept his HCV infection a secret from his employers and colleagues. He was afraid it would cost him his job. While he was in full-time employment, he struggled with tiredness and severe headaches, which was reflected in his diminishing salary. Eventually, he left and became self-employed, which meant that he was able to rest when the tiredness became overwhelming. Financial instability was a risk worth taking in order to manage his condition. I am convinced that remaining in full-time employment would have had disastrous repercussions on his health and wellbeing.

35. I have not been personally affected by any stigma; however, I do not disclose Phillip's infection to many people, therefore respecting his wish to privacy. Only with Phillip's approval, have I disclosed his condition to my very close friends.

36. Phillip's education and academic performance have been affected by his illness, as he missed out on lessons and exams, due to poor health.

37. His career and job opportunities were also affected, as he had to give up full-time employment at the very end of 2010 and become self-employed. This also affected our finances, and even now he is struggling to do more than a couple of hours of work per day. This side of things has been affected by both his original infection and the treatment. Subsequently, our financial situation was at times difficult and his grandparents had to help us out numerous times.

38. Whenever Phillip needed a blood test, the forms had a large bio hazard sticker on them, which of course made him anxious and ashamed in front of other patients. There was also an incident during a tooth x-ray, whereby a nurse would not take the gauze out of his mouth, due to the fear of contracting HCV.

39. Having three children is demanding and unfortunately he is not able to do a lot of things, like playing football with his son or taking them to the park on his own. Going out for a couple of hours was and still is a strain; physically and mentally due to the headaches and fatigue. Playing with the children leaves him breathless and exhausted.

40. Phillip's HCV-related fatigue has put a big strain on our relationship and family life. I had to take over most of the responsibilities in our household and family life. Due to my own medical condition (ankylosing spondylitis), all this is becoming increasingly more difficult to manage. I am very anxious about Phillip's health and wellbeing.

41. Chores around the household are equally difficult. Certain things that I cannot do on my own take months to be sorted. It is something we had to learn to accept and now we concentrate only on priorities that need an immediate action.

42. Also, our children are missing out on a lot of fun activities, due to Phillip's fatigue. I feel overwhelmed by all the things I need to sort out; my stress indirectly affects our family.

43. As I do all the driving in the family, Phillip has considered applying for his driving license multiple times. However, he was not able to do so, as it proved to be too much for him, with his constant fatigue.

Section 6. Treatment/Care/Support

44. As mentioned above, Interferon and Ribavirin had been offered to Phillip, but he refused them due to the fear of its side-effects. When Harvoni came out he had problems obtaining it, but he did eventually get it.

45. Only two years ago, Phillip was offered counselling while attending a meeting at the Haemophilia Department of SRH. He politely declined. I was not offered any support.

Section 7. Financial Assistance

46. We found out about the Skipton Fund from Phillip's uncle, who was also a haemophiliac infected with HCV. Phillip came across a post by Tainted Blood that contained information about the Caxton Foundation. A few years later, he received a letter from EIBSS informing him of the change from the old schemes to the new NHS-run scheme. The nurse from the Haemophilia Department at Sheffield Royal Hallamshire Hospital helped him to fill in the forms.

47. Phillip received one-off Stage 1 payment of £20,000 from the Skipton Fund in or around 2005. He has received from the Caxton Foundation £350 in 2014 as winter fuel payment, that then increased to £500 yearly (increases with inflation each year), £291.67 monthly income top-up since 2015~~,~~ and from 2017 £250 stage 1 HCV monthly payments.

48. Phillip received from EIBSS £1,500, which started in 2018, and a monthly income top-up of £695 since 2019. At the present time, Phillip receives £450, child supplement, and £2333.33, Stage 1 and SCM.

49. Phillip never applied for any grants or emergency funds, due to the complicated and drawn out application process. In contrast to the other schemes for ongoing ex-gratia payments, the EIBSS required a lot of extra paperwork and documents. We both found the process overly complicated. I do not have any other observations about the various Trusts and Funds, as I have not personally dealt with them.

50. Only on a couple of occasions, Phillip was queried by the EIBSS. Other than that, we were lucky enough not to have encountered any significant problems.

51. In order to receive the lump sum of £20,000 ex-gratia payment from the Skipton Fund, Phillip had to sign a waiver about not being able to claim for any other infections or viruses in the future.

52. I have not received any financial assistance from any of the Trusts or Funds.

Section 8. Other Issues

53. I do find it concerning that Phillip's records have been destroyed. I am aware that there are guidelines on how to handle and store medical records of people with genetic illnesses, but they are open to interpretation. I believe that the medical records of the people who have any ongoing condition should not be destroyed.

54. Around 2 or 3 years ago, I attended a hospital appointment with Phillip in order to enquire about the discrepancies regarding what Phillip was injected with prior to his teeth extraction surgery in 1981. The NHS staff member who attended us seemed to be rather irritated with us for probing into this issue, but it really bothered Phillip that every source said something different. He has every right to enquiry about his own medical treatment. The medical staff then said that we should put the past behind us, as he was in a reasonable state of health and therefore should only concentrate on the future.

55. I found it strange and inappropriate that this advice came from a NHS staff member, as it is crucial to remember the past to prevent any such things from happening in the future. I also felt like they were trying to tell us to be grateful that Phillip is still alive and that he is in a lot better position than a lot of other people. I do not think that they should have dismissed a person like that.

56. Another thing which I find rather strange is that normally he would have once a year medical appointment, whereby he would have all his 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 our own comfort, as it means that Phillip does not need to travel to the hospital for his yearly appointments. He could chat with a nurse about his health and then they could arrange for him to have any blood tests done at our local GP. He recently had his telephone appointment, which was arranged a year ago, and we both found it rather disappointing and disturbing. The nurse who rang him enquired about his very distant relatives who also are haemophiliacs. She asked for their names and surnames, asking him even for the correct spelling of their names. I do not consider this to be of any relevance to his appointment. When Phillip asked them why they needed that information, he was told that it would go on his file and that they would send him a Haemophilia card that he could carry with him.

57. I think that the nurse realised that we were unhappy with how the appointment went, so she suggested that Phillip can be put up on the list for yearly face-to-face appointments, which he agreed to. He was also advised to check our daughters, to see whether they are Haemophilia carriers. Once again, Phillip asked to have a liver scan. The nurse said that she will try to arrange it. We have not heard anything back yet. It feels to me like the Haemophilia Centres are starting to distance themselves now, that Phillip has had his treatment.

58. I have received the Chairs determination, refusing to designate me as a Core Participant to the Inquiry which I understand means Phillip will not be able to discuss or disclose information or documents with me unless they are made public at a later stage. I find this decision shocking as it will prevent me from being able to support Phillip at a time when he needs it most and it interferes with the rights of our family to communicate with each other. I think it is morally wrong for the Chair to use the power of the law to do this.

59. Up until now I was happy with the way the Inquiry was being conducted, but now I am quite worried that it will not be fair to the victims of this tragedy.

Anonymity, disclosure and redaction

60. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry. I do not wish to be called to give oral evidence.

Statement of Truth

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

Signed.... GRO-C ....

Monica Oana Hayes

Dated: 09.08.2019