IRO

Witness Name: Hayley Baxter
Statement No.: WITN0544001
Dated: 19th February 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF HAYLEY BAXTER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 2nd January 2019.

I, Hayley Baxter, will say as follows:

1. Introduction

1. My name is Hayley Baxter. My date of birth is GRO-C 1969 and my address is known to the Inquiry. I work as a case manager for the Children's Services in the Youth Offending Service and I have 3 children.

2. I intend to speak about my eldest daughter Charlotte's infection with Hepatitis C (HCV). In particular, the nature of her illness, how the illness affected her, the treatment received and the impact this had on Charlotte's life as well as mine, her siblings and my mothers' lives.

3. The Inquiry has made me aware of the anonymity process and I have elected not to be anonymous.

2. How Affected

4. My daughter was infected with Hepatitis C as a result of numerous blood transfusions during her treatment for Lymphoblastic Leukaemia from the age of 3.

5. Charlotte was born in GRO-C 1986. The birth had few complications however Charlotte was born with Down's Syndrome.
The doctor was very insensitive and tried to persuade me to put her up for adoption. I was told to expect a multitude of problems due to her Down's Syndrome. However, Charlotte was really healthy and was meeting all of her targets. She was walking and talking earlier than predicted. She was a very sprightly child and overall was doing quite well.

6. Child psychologists thought that a specialist school would be necessary however after some persuasion we were able to get Charlotte into mainstream education at an observation unit. She was 3 years old and attended full time, it was excellent.

7. In late September of 1989 Charlotte started to look really unwell. Her skin was becoming quite yellow and her temperature was spiking. Where Charlotte would usually be running around, she was lethargic and sleepy. We went back and forth to the GP being told she had a virus.

8. By the end of the 4th week Charlotte was referred to Dr Blankson the consultant paediatrician at the Prince Charles Hospital in Merthyr Tydfil. They quickly took Charlotte's blood and carried out a lumbar puncture which was awful. Her haemoglobin was down to 4 where it should normally be between 11 – 18.

9. On 4th November 1989 Charlotte was diagnosed with Lymphoblastic Leukaemia.

10. Dr Blankson rang Llandough Hospital and arranged a bed for Charlotte. We were taken down by ambulance and were met by the team of Dr Aileen Thompson, the oncology consultant in charge at that time. We remained in Llandough for the next 4 months.

11. Due to Charlotte's Down's Syndrome the doctors had a meeting to decide whether they would even treat her because chemotherapy was so expensive. This was shocking. They saw how much Charlotte was loved and decided to treat her.

12. The hospital had a protocol in place at the time where the regime of treatment was chosen out of 4 options, at random whilst Dr Thompson was away. Charlotte was placed on what was known as Regime (D).

13. From November 7th 1989, Charlotte was blasted intensely with chemotherapy. As her blood count was still so low she was transfused at the start of the treatment.

14. Charlotte's treatment made her really really sick, her body could not cope but her Leukaemia was reacting well. Chemotherapy attacked her bone marrow, and her white and red blood cells stopped producing. Further transfusions were needed throughout the treatment to counter the effects of the therapy. She was transfused with platelets, white blood cells and red blood cells. During the first 4 months of treatment Charlotte probably received between 30-50 transfusions.

15. No advice was ever given to me about the risks that transfusions carried. I had no idea there was a possibility of Charlotte contracting an infection. I was simply grateful for anything that helped cure the

Leukaemia.

16. Dr Thompson was appalled at what she found on her return. Regime (D) was having a severe impact on Charlotte resulting in Charlotte developing infections and therefore needed to be treated for these and 7 types of intravenous antibiotics were administered in addition to the Chemotherapy with the cannulas coming out of both hands and both feet. She immediately took Charlotte off this regime and treated her accordingly.

17. The appropriate treatment continued on a cycle with chemotherapy and steroids monthly and Charlotte slowly began to recover. We would be in and out of hospital as her health was now generally poor. She even contracted shingles at one point and still needed her blood testing weekly.

18. In 1994, when Charlotte was 8 years old, we reintroduced her to school however by this point we had to give up on the mainstream education just to get her healthy, happy and looked after. She attended GRO-C for the remainder of her school years.

19. For years this maintenance treatment continued. In February 1995, the doctors were confident that Charlotte was 5 years clear of Leukaemia. She would always be tired and constantly complaining of having a bad stomach. She was not bothered or enthusiastic with anything anymore and she always had headaches. It was like the life was sucked out of her, but she no longer had Leukaemia.

20. We had finally got Charlotte into some normality when in the spring of 1999, a letter arrived at my mother's bungalow from the Blood Transfusion Service. It stated that through a lookback programme they believe Charlotte had received blood from a donor who was subsequently found to be infected with a particular strain of Hepatitis

C. The letter advised that she be tested.

21. The way we were informed of the infection itself was terrible. The letter just arrived through the door and dropped on the mat like a bombshell. It was devastating. We have searched but have been unable to find the letter as Charlotte has moved house.

22. It was thoughtless and a total disregard to patients who were already vulnerable having needed transfusions in the first place. We could have been told that we needed to go in and see a doctor, at least that would have been in person. We were left shocked with no one to ask questions to and just our own knowledge of what to do. It was totally irresponsible and the people who sent these letters have no idea of the impact that it has caused people on a daily basis for all these years.

23. We went straight to the GP for blood tests, which are traumatic for Charlotte as she has bad memories from the Leukaemia. These came back within a week as positive for Hepatitis C.

24. We were given very little information about the infection. We received a leaflet on Hepatitis C from the doctor and that was really frightening. We had to read that the infection could be fatal, that liver cancer was a common effect and that HCV was most commonly associated with drug use.

25. We spoke to the GP about the chances of contamination having occurred. We were told it was a fatal disease that they did not have a cure for it yet. We were beside ourselves, she could potentially die from something again and myself, her sisters and my mother could have all been exposed.

26. When I was informed of the infection I was beside myself with fear and anxiety. I went into meltdown. You immediately envision all the

times we changed her nappies or when she had nose bleeds, or shared baths with her younger sisters. I kept panicking and thinking what if I have unintentionally transferred this virus to my other children and or us.

27. We were referred to Dr Evans, the consultant liver specialist at the University Hospital of Wales in Cardiff. He confirmed the diagnosis. The news was delivered well and the specialist nurses were a good support. They explained that it is possible to have had no symptoms for 10 years. It did occur to us that her tiredness and general ill health after she had been cleared of Leukaemia was likely to be caused by the Hepatitis C.

28. On the whole we were not told adequate information about the management of the infection. The HCV leaflet mentioned times when the virus could be transmitted. These included sharing toothbrushes or razors. It also mentioned that when taking drugs, you must use clean equipment – again the illness had this association with drug use.

29. I was extremely worried as we had spent over 10 years not using gloves or being aware of the risks we were subjecting ourselves too. I had 3 young daughters who would share baths and at times toothbrushes if they had mixed them up. There are many occasions where the girls or myself could have been infected. This gave me panic attacks in addition to the constant anxiety of Charlotte having a potentially fatal virus.

30. In Charlotte's case, because she was young, there was not going to be any worry over intimate relationships. However, I think of how many times toddlers fall and cut themselves, or need their nappies changing. You don't think twice about dealing with it especially with

two other small children, but these activities were all risky.

31. On one of our visits to the University Hospital of Wales, about 3 years after we found out about the infection, we were finally told that my mother and I should be tested ourselves. Luckily, they did it there and then and after a week's wait we were found to be clear.

32. '*Fortunately,'* for us, because Charlotte's Leukaemia left her with a weak immune system, we were already very careful with hygiene and cleanliness. After being informed of the infection we were even more careful.

33. Every part of Charlotte's personal care is dealt with by someone else be that myself, my mother or other carers. We then made sure we were all wearing gloves. However, most of these management practices were from our own experiences with nursing and not from any medical staff. We were actually told not to panic too much instead of being told how to manage the infection.

3. Other Infections

34. I believe 100% that Charlotte was only infected with Hepatitis C as a result of the blood transfusions.

4. Consent

35. As far as I am aware Charlotte was not treated or tested without my knowledge, consent or without as much information as possible being given to me.

36. Charlotte was treated for both her Leukaemia and HCV through clinical trials but both were consented to by myself as her mother and Power of Attorney.

5. Impact

37. When we were informed that Charlotte was HCV positive I felt total shock, panic and isolation. It was frightening and I did not know what to expect.

38. In terms of treatment for HCV the doctors explained that they did not have much success with those available at the time. Interferon was discussed but the doctors did not think it was suitable for Charlotte as she had such a weak immune system due to her Leukaemia. The decision was made to monitor Charlotte and run fibro scans to see the condition of her liver. It was enlarged, scarred and she had cirrhosis.

39. As there were no appropriate medications on the market Charlotte had to have regular appointments at the University Hospital of Wales every 3 months to monitor her. These went to every 4 months and then every 6 months. She would have her blood taken at each appointment where she would be crying and screaming and need to be held down. The specialist nurses, Tara and Sara, at the hospital were wonderful.

40. In the spring of 2004, when Charlotte was 18 years old, Dr Evans at the University Hospital of Wales decided that we should revisit the idea of treating Charlotte with Interferon. Her health was deteriorating and it was necessary if we were going to tackle the HCV.

41. The treatment was composed of a 6-month course of Interferon injections weekly and these were administered by the specialist nurses. This was combined with Ribavirin tablets and this was 4 tablets taken 3 times a day.

42. We were informed that the side effects could include depression, general un-wellness and a reduced immune system. They warned us that they had not had a lot of success with the medication.

43. The actual side effects were very different and I remember them being similar to the side-effects of chemotherapy. Charlotte was so poorly. She had a very low mood, no motivation and was generally miserable. She was crying all the time and had no appetite. This was difficult as the pills were to be taken with food. She had severe joint pains and would complain that she had pains everywhere. Her already weak immune system was being knocked down again.

44. In August 2004, at the 12-week review, they confirmed that Charlotte's strain of HCV was not reacting to treatment so they immediately decided to stop treating her. It would not have been fair on her to try any longer. We returned to monitoring every 4 months, with scans every 6 months and blood taken every time.

45. Charlotte's health saw a significant deterioration in 2012. She also had an underactive thyroid meaning that she gained significant amounts of weight. Charlotte was so tired. She had no interest in anything and would not go to college or swimming. Her menstrual cycle would stop and start and she would constantly complain of head and stomach pains. She even began to suffer from gout.

46. Throughout this time without medication, we kept an eye on any clinical trials for HCV treatments in other countries. In February 2015, Dr Evans and Dr Freeman at the University Hospital of Wales called us in for a consultation for a new clinical trial because Charlotte's health was declining so quickly.

47. Charlotte was given 1 of 6 spaces on the trial. I was extremely reluctant to let her try as her experiences previously were so awful and she had such a horrific experience on the Interferon. I was so frightened; I have always had to make all medical decisions on

Charlotte's behalf and this was no different. We had nothing more to lose and so I gave my consent.

48. The trial began in February 2015 and was 12 weeks long. It consisted of 16 tablets which had to be taken at the same time every day. There were 2 main tablets and these were taken in conjunction with other tablets including Ribavirin again. I believe the trial drug was called Sofosbuvir.

49. We were told that they were not sure of the side effects as it was a trial but they did not expect it to be anywhere near as bad as Interferon. They were just hoping her body would tolerate the drug.

50. The actual side effects were hard to tell because Charlotte's health was so bad from the infection itself. Her appetite was not good and her mood was low. She certainly tolerated these drugs much better. She was much more on the ball and you could tell that she was brighter.

51. Every week for 12 weeks she had her blood taken and within the first week her viral load had already decreased.

52. At the end of the trial, her 12-week scan revealed that no HCV could be detected. She still had liver scarring and cirrhosis but no other sign of Hepatitis C.

53. Charlotte now has liver scans every 6 months at the Prince Charles Hospital in Merthyr Tydfil under Dr Neville.

54. Mentally the impact of the infection on Charlotte has been huge. Her whole life has been affected from the age of 3. She was never able to achieve her potential, whether that was physically or emotionally.

55. Personally, I feel very upset and angry that Charlotte had to undergo so many more years of needles, tablets and suffering needlessly. There are so many added complications due to her lack of understanding. I am, of course, grateful for the treatment she had. She suffered so much as a child with Leukaemia but her potential outcomes in life were ruined by the infection.

56. The impact emotionally and physically on myself and the rest of my family is also huge. Once we were aware of the infection we became hyper vigilant and unable to relax. As we did not know much about the infection, other than it was fatal, it added a lot of anxiety to our lives. We even stopped sharing drinking cups for example.

57. My mother and I shared the responsibility and care of Charlotte for a long time. Due to Charlotte's Down's Syndrome she has a lack of understanding and therefore we are responsible for everything. As her parent and carer, we supervise every aspect of her care as Charlotte would not be able to take her tablets on time or be able to attend her appointments.

58. It is very difficult to put into words how it all makes you feel. I am now at the stage where I feel really angry. This has been inflicted on Charlotte and us as a family through the negligence and disregard of others. They have no idea of the impact on her daily life and the rest of our lives. It is heart breaking to see Charlotte everyday feeling terrible but with no idea why she does. With hindsight we can see the differences in her health and how even before we knew of the infection she was yellow and itching for example. We now know these are effects of HCV.

59. It impacted on her quality of life and her potential. It dictated every aspect of her life. She had overcome such huge hurdles with her Leukaemia, was reaching her own milestones and then was brought

back square one.

60. We did not have any difficulties in accessing any treatments. Dr Evans, Dr Freeman, Tara and Sara the specialist nurses in Cardiff were great and would be fighting Charlotte's corner and pushing for her to access any treatments possible.

61. Charlotte's HCV status did not impact her access to other treatment. However, she was treated differently. When we informed our local dentist, he acted like she had the plague by suddenly wearing a gown and mask and gloves. We could see the fear on him. Other doctors and nurses would wear two pairs of gloves to touch her. Thankfully as time went on and people learnt more about the infection these practices stopped.

62. Charlotte's social life was also impacted and this made me upset and angry. She is already very vulnerable but we felt we could never support potential relationships or facilitate her social life. I would think of the other parents and their reactions, but it is hard because she wants everything my other daughters have. In her teenage years it was extremely difficult.

63. For years I was on guard and did not tell anyone about our situation. I didn't want Charlotte to have to be more disadvantaged than she already was. We were told that we didn't have to tell anyone because if schools and hospitals, for example, were following their own safety practices then there would be no risk to them. We told people that came to care for her but not many people in our wider social circle, at least to begin with. There was a lack of understanding around Hepatitis C and such a stigma that people would have probably shied away from us.

64. My job has involved a lot of drug awareness courses and so I would hear discussions of HCV and it was always in a negative light related

to drug abuse. I would sit there thinking of my daughter and that innocent people were infected too.

65. Since being treated and cleared of the HCV we are much more open with it. I am annoyed, but very proud of Charlotte and all that she has overcome and do not feel the stigma as we have previously. I feel like shouting to the world of how proud I am of her.

66. My mother and I have kept our social lives restricted. Charlotte's additional needs meant that she needed to be fully cared for, however had she not been infected she may have had much more freedom and independence. We did not like to leave her in the care of others because the care she needed was over and above the package provided for a young woman with her level of needs.

67. Charlotte now has her own tenancy in a bungalow and other carers who are employed to work as personal support assistants. This has given me and my mother a break and some separation for Charlotte so that she can learn more about life independently from us.

68. With regard to Charlotte's education her infection has changed the course of her life completely. Charlotte was in mainstream school and surpassing her goals before all of this occurred. We then focussed on recovery and happiness because she had missed so much school with the Leukaemia. Underneath she was infected with Hepatitis C which was making her so ill. She was uninterested in schooling for a long time, even when she was on medication, and her development has therefore been much slower. If she had not had 27 years of this her outcomes would have been greatly improved.

69. My mother sacrificed her nursing career to care for Charlotte and so that I could keep my career. One of us would have had to stop working and so my mother chose for that to be her. I was able to

continue and my job was understanding when I needed time to take Charlotte to appointments. When the service I worked for merged with the neighbouring region this became difficult. I had to make up the cover and ensure I had time off in lieu left over.

70. **GRO-B**

6. Treatment/Care/Support

71. The treatment we received regarding Charlotte's HCV in hospital was good. Our main support has been through the specialist nurses at the University Hospital of Wales. They would discuss Charlotte's case with the consultants constantly and talk us through everything. The nurses and consultants were very approachable and would make us feel really welcome. The nurses would treat Charlotte really well and did not put multiple pairs of gloves on before they touched her.

72. Whilst Charlotte was on the clinical trial there was support available to us through the pharmaceutical company. There was a lady we were able to speak to if we wanted throughout.

73. Although we have not sought any psychological support or counselling, none has ever been offered to us.

74. I have accessed counselling through work. Last year when the Inquiry was announced I began to feel so angry and anxious. It was horrible when we found out how many people were infected and that the government might have known. I attended 3 sessions.

75. I can confirm that the Inquiry team have made me aware of the psychological support that the British Red Cross can offer me and my family; I have received their contact details and I will consider utilising their services.

7. Financial Assistance

76. I became aware of the Skipton Fund through the specialist nurses at the University Hospital of Wales. The financial assistance is now through a scheme called the Welsh Infected Blood Support Scheme (WIBSS).

77. **GRO-B**

78. The process of applying to Skipton was not a particularly difficult process. We had to have the doctor fill out documentation. In addition, they had to assess Charlotte and her level of liver damage in order to be accepted for stage two payments.

79. There were no preconditions imposed on the payments however we are aware that they are only ex gratia payments which could be removed at any moment.

80. This money is life changing and allows Charlotte to live as independently as she possibly could. If she was just on the income support provided, then she would have no social life and would be on the poverty line barely able to afford essentials.

81. This being said, nothing will compensate for the suffering she has had and could still have as a result of the infection. They are giving money which helps her to have a better standard of living, but it is

nothing compared to what she has lost in life. We are grateful, but it is pittance. With the financial assistance not being a commitment, it is worrying.

8. Other Issues

82. I contacted the Inquiry because I felt that we needed a voice. I know that Charlotte is one of many but her story maybe slightly different as she is unable to have a voice of her own. I want to do justice for her and I didn't want to just wait for the outcome of the Inquiry, I want her story to be told. Charlotte was disadvantaged from the beginning with her additional needs but this has meant that she has never been able to reach her full potential or live her life to the fullest.

83. We feel helpless and powerless. For years I thought I should just be happy that Charlotte's Leukaemia was cleared (which of course we are), and that this was an outcome I had to accept as a result. That is wrong and I should not have to feel that way.

84. How on earth could this have happened? Someone somewhere must have known something. These rash decisions have impacted on vulnerable people and somebody has to be held to account.

Statement of Truth

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

Signed **GRO-C** ____________

Dated 19 March 2019.