Witness Name: HAYLEY JANE SIMPSON
Statement No.: WITN0082001
Exhibits: WITN0082002 – 003
Dated: 22nd April 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF HAYLEY JANE SIMPSON

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 February 2019.

I, Hayley Jane SIMPSON, will say as follows: -

Section 1. Introduction

1. My name is Hayley Jane SIMPSON. My date of birth is GRO-C 1978 and my address is known to the Inquiry. I am a recipient of infected blood from which I contracted Hepatitis C. I intend to speak about my Hepatitis C infection and the nature of my illness, how it affected me, the treatment I received and the impact it had on my life.

Section 2. How Infected

Hepatitis C Infection

2. When I was 3 I underwent surgery for congenital hip displaysia at Manfield Orthopaedic Hospital in Northampton. The surgery I had was a significant orthopaedic procedure; I had one main operation and a few

smaller, peripheral operations to secure pins in my pelvis. My earliest memories are of being at hospital, however because I was so young I was unaware of what was happening.

3. I was admitted to hospital approximately 12 weeks prior to my main surgery because I was undergoing traction in order to correct my hip placement prior to surgery.

4. During the main operation I received a blood transfusion of 300 millilitres. I am unsure of why I needed the blood transfusion; this could have been because I was quite small from the lack of eating prior to the operation or because there were complications during surgery.

5. My mother does not recall any of the medical staff explaining the risks of my surgery nor does she recall staff noting that I may need a blood transfusion.

Hepatitis C Diagnosis

6. In 1997 after finishing my A Level exams, I donated blood. At the time, I was not suffering from any symptoms of Hepatitis C nor did I know that I had received a blood transfusion as a child.

7. Following my donation a letter was sent to me at my parents address from the National Blood Service. When my Mum and Dad told me about the letter I asked them to open it and read it to me down the phone. The letter informed me my blood had been tested at the point of donation and that I was positive for Hepatitis C; the letter advised me to see my GP.

8. I did not receive any follow up to this letter from the blood service – I dwell on the fact that this letter could have been lost in the mail and I wouldn't have known that I was infected. At that time I did not have any symptoms and I recall thinking that because I was feeling okay, that maybe I was a carrier.

9. I was only a few weeks into my first semester; everything was new and the news came as a huge shock. I did not know what to think or how to act. I did not want my university life to suffer because of this news.

10. After I received the letter I saw the university doctor (a GP) and together, we went through all the possible ways that I could have been infected. I recall that my GP assumed that I must have had a blood transfusion during my surgery as I had no other exposure to infection. I did not get a confirmation of how I was infected until I requested copies of my medical records when I applied for the Skipton Fund in 2007. Following this diagnosis, my doctor referred me to Leicester Royal Infirmary to see a Hepatologist.

11. My doctor provided me with some basic information regarding the risks of infecting others. I cannot recall the specific but it was along the lines of being careful about unprotected sex and to make sure that I did not share razors or toothbrushes with anyone. I do recall my Hepatologist going into more detail about how to prevent passing the infection to others.

12. I think I was lucky to find out when I did because I had youth on my side. For example, I wasn't drinking alcohol throughout my childhood and when I found out about my diagnosis I immediately cut down my intake.

Section 3. Other Infections

13. I do not believe I have contracted any other infection as a result of being given infected blood.

Section 4. Consent

14. When I donated blood I remember being in the queue and reading posters about eligibility and the exclusion criteria for donating. I think I may have consented for my donated blood to be tested.

15. My mother does not recall any of the medical staff explaining the risks of my surgery nor does she recall staff noting that I may need a blood transfusion.

16. As I was already at hospital undergoing the 'traction' she received a phone call to inform her that I was ready for my surgery. She recalls everything moving quickly and by the time she arrived I was already in being prepared for surgery.

17. She does not recall if any of the risks of the surgery or blood transfusions were ever explained to her.

18. I can confirm that I have consented to all treatment received.

Section 5. Impact

19. Following my referral to see a Hepatologist at the Leicester Royal Infirmary, I had a liver biopsy in June 1998 and went back for my results at the beginning of October when I was starting my second year of university.

20. When receiving my results in October I saw a locum doctor who informed me that my liver was damaged and that I would need to immediately start Interferon treatment. I had heard that this treatment would give me a 30% chance of successfully clearing the virus and that the side effects were debilitating. When I called the Hepatology Nurse a couple of weeks later to arrange the start of treatment, I was informed that there had been a mistake with the biopsy scoring and my liver was actually fine. Therefore, I would not need treatment at this time. This was a relief but I had been through hell unnecessarily.

21. I had another biopsy at the Leicester Royal Infirmary in 2000 just after I left university and my results were again okay.

22. My third liver biopsy at the Leicester Royal Infirmary was in October 2004 and I went back for my results just before Christmas. Although the consultant had not calculated my test counts he said that he thought I would be alright and to come back to the clinic in a years' time.

23. In January 2006 I went in for another check-up and I was told that my 2004 biopsy actually showed that I was developing fibrosis on my liver. The doctor said that as there was fibrosis it meant that the infection was active and that I should begin treatment.

24. I was told that I needed to begin Interferon and Ribavirin; these treatments had become better over the years in terms of success rates but still had debilitating side effects. I had started a new job in September 2005 so I chose to delay starting treatment until July 2007.

25. The Interferon was a weekly injection which I had to self-inject. I had to learn how to self-inject however, this did not bother me. I recall thinking that '*if this is what I needed to get better, I needed to get on and do it*'.

26. I suffered from side effects of the treatment. I felt fatigued and had aches and pains all over my body. I had to take a day off work per week to help me cope with the physical impact, but I had really understanding employers and so my work did not suffer. The worst side effect however was depression I was told that this was a common side effect of the treatment. I became very low and recall that I could not stop crying, even in public places. I once cried on the bus and people were looking at me.

27. I was taken off treatment after a 4 months as my body was not responding to the medication and my employer kindly allowed me to work part-time for 3 months whilst I recovered. After this I returned to work full-time.

28. After some time, new Hepatitis C treatments were developed. However, these new treatments were initially only available to patients with advanced liver diseases. I understood the need to prioritise these

patients, however it was horrible waiting and knowing that there was treatment out there with a 97% success rate.

29. I had learned from online forums that it was possible to buy the new treatment online and not wait for the NHS but this would cost approximately £80,000. I heard that some people were importing the generic treatment from India and Bangladesh but I decided against this. My thought process was that whilst I did have to wait for treatment on the NHS, I would be able to follow up with the consultant and have the necessary scans and tests. Additionally, buying treatment online was a significant risk.

30. I constantly followed up with my consultant to see when the treatment would be available. Once the NHS were satisfied that those with advanced stages of liver disease had been treated they started treating everyone. Shortly after, I began my 12 week course of Viekira Pak treatment in May 2016.

31. Although the side effects of the Viekira were not as severe as those that I had experienced during my first round of treatment I recall being tired, nauseous, losing weight and suffering from a persistent cough. I was working part time at this stage and did not need to take any time off work.

32. I finished my treatment in August 2016 and was informed that I had cleared the virus at the end of 2016. I was never seriously ill from Hepatitis C but I noticed that I have more energy after the second round of treatment.

33. From October 2017, I went back to full time work for approximately 18 months. I know that I would not have managed working full time and having Hepatitis C, this is because I have always tired easily and why I worked part time from January 2011 to October 2017. Having had Hepatitis C for most of my life, it is impossible to say whether this was due to the virus as there was no clear before or after comparison. I do

feel that since clearing the virus in 2016 my energy levels have improved.

34. I found that I did not have the 'normal' symptoms of Hepatitis C so I do not think that the symptoms, for me, are reliable; you could feel that you have relatively good health but your liver could be damaged. After being cleared, I felt like there was no cloud hanging over me; I was not living in fear with what is going on inside of me questioning whether I had cirrhosis or whether I would need a liver transplant. I did not have to worry about what the future would hold.

35. I have felt stigmatised by people when they have found out about my Hepatitis C infection. The worst stigma I have felt came from a Senior Consultant Hepatologist, who should have known better. It was when I went for a routine check-up in my mid-20s; I was wearing casual jeans and hoodie and I when I went into the consulting room he looked me up and down and said '*How did you get Hep C? Recreational drug use was it?*' This Consultant should have known better but I did not make any complaints for fear that my treatment and care would have been affected. This was the only 'in your face' example of stigmatisation that I suffered. I was lucky that I was not on the receiving end of too much stigma; but it was a worry.

36. I was always worried about what people thought when I would disclose that I was infected with Hepatitis C; despite this I started being open about my diagnosis, it was through no fault of my own but through infected blood I received when I was 3 years old. When I did tell some people, I was warned to be careful who else I disclosed my diagnosis too, it was from this point I became more guarded.

37. With regards to my employment, I have always declared my diagnosis on the occupational health and safety forms I completed prior to starting any role. My employers were always aware of my diagnosis and were

supportive however, I was worried that some of the families I worked with would not want me working with their children.

38. I feel lucky to have been diagnosed young, before any harm had come to be. I want to raise awareness and encourage people to come forwards and be tested, which is one of the reasons I gave the interview (**Exhibit WITN0082002**).

39. I met my partner when I was 17 which was before being diagnosed. We went through it all together, I feel lucky to have met him when I did and grateful that I did not have to have a conversation with him about my Hepatitis C. If I was single, I do not know how I would even start that conversation with a new partner without them running in the other direction. My partner was tested when we went through the fertility treatments, this testing is standard for every couple. He was cleared at this stage but he has not been checked since I was cleared of the virus.

40. I have not had any issues with dental treatment however I was refused a tattoo. The tattoo artist who I first went to see was not confident in dealing with someone who had Hepatitis C, I just thought that it was lucky for him that I did disclose this. I did get a tattoo from another tattoo parlour, the artist asked me to come in at the end of the day so that a thorough clean could be performed afterwards.

Fertility Treatments

41. When my first treatment for Hepatitis C was cancelled, I started counselling to battle depression. I was fortunate that my employer at the time offered these counselling services. Through counselling I was able to evaluate my life and questioned what I wanted out of it; I came to the realisation that I wanted to be a mother and to have a family. At the time, my job was to help young children whose parents had chronic illnesses and I knew that if I wanted to be a parent I would want to be healthy.

42. My partner and I discussed with my Hepatologist the risks involved with the pregnancy and we were informed that there would be a 5% chance

that I could pass on the virus onto a child. This discussion took place before I was cleared of Hepatitis C.

43. It was at this point that I changed hospitals, transferring to Northampton as if I was to have children, I would want to have both my Gastroenterologist and my Obstetrician located at Northampton.

44. Starting a family became the focus of my life, however it did not turn out the way I envisioned. I had fertility problems and have not been able to have children. It always nagged at the back of my mind that the Hepatitis C would not just be linked to issues with my liver but also with my fertility. I have had several rounds of fertility treatment – inter uterine insemination (IUI) and in vitro fertilisation (IVF) – and one miscarriage. I have some minor gynaecological problems but these alone do not explain why the fertility treatments did not work and I can't help but feel that the Hepatitis C virus may also have played a role in my infertility.

45. The fertility clinic in Northampton stated that they had a policy that if a woman was infected with Hepatitis C and/or HIV, the clinic would not freeze their embryos due to the risk of contamination. Therefore, I was only able to have the fertility treatment of IUI, completing 3 rounds at Northampton with differing results.

46. Due to the Northampton clinic's policy, my partner and I had to find a different clinic that would perform the IVF treatment. The Leicester clinic stated that they would provide me with the IVF treatment I wanted this was on the NHS but as the clinic was in Leicester I had to travel every other day for scans and tests. This extra travel was tiring and added unnecessary stress to an already stressful stage in my life.

47. Due to the change in clinics, there was a lack of continuity in my treatment. During the first round of IVF, 8 eggs were harvested but none fertilised. It was after this that the Leicester clinic advised that instead of the standard IVF treatments I should have had the specialised IVF treatment of intracytoplasmic sperm injection (ICSI) fertility treatment –

this is where the sperm is directly inserted into the egg which increases the chance of fertilisation. If I had completed the ICSI treatment earlier, I might have been able to have had a fertilised egg. After completing this treatment I was diagnosed with premature ovarian failure, that is, my ovaries ran out of eggs too soon.

48. I can't prove that the Hepatitis C virus has affected my fertility but if it did then it would be the single most devastating consequence of being infected; it's had a huge impact on my life.

49. During my fertility treatment I kept in contact with my Gastroenterologist who talked to me about clinical trials for the Hepatitis C that were going on. I was interested but I could not participate as I wanted to get pregnant and the trials do not accept women who want to get pregnant, or are pregnant. It was through him that I found out about the new Hepatitis C treatment, Viekira Pak. After being diagnosed with premature ovarian failure, I sought treatment for Hepatitis C.

Section 6. Treatment/Care/Support

50. When my first treatment for Hepatitis C was cancelled, I felt that I was facing an incurable disease. I was offered counselling through my employer at the time but not from anywhere else. This counselling was very helpful and I needed it; I was lucky that my employer had this service on offer.

51. Additionally, I have accessed counselling through the Hepatitis C Trust after the government released funding for contaminated blood victims. Although, I believe I have not claimed my full quota of these sessions. I think this is because, although I feel that further counselling would potentially be helpful to me, I am aware that counselling is a big commitment emotionally. I am currently hesitant to enter into that zone, as I am afraid of feeling worse again before feeling better.

52. I have self-funded some counselling sessions in between my employer funded and government funded sessions. I would have benefited most from the government funding sessions if it had been made available sooner.

53. Counselling helped me evaluate where I was at in life and what I wanted from life if Hepatitis C was to impact my life long term. It was through this counselling that I realised that I wanted to have a family.

54. When I came off the Interferon treatment, I still had to battle with the depression and my GP certified me with 3 weeks off work. Additionally, I was told that my depression would be better because I would not be on the treatment but it was not that simple.

55. I believe that I may have had the tendency to be depressed but whether this was exacerbated or caused by the Hepatitis C treatment, I cannot be sure.

56. Following diagnosis, I did try and make lifestyle changes to get the feeling of control back and to give me best chance of being positive. I cut down on alcohol when I was first diagnosed and then in 2006 I cut it out completely. Additionally, I implemented a healthy diet and exercise routine.

57. I recall The Hepatitis C Trust running 'Health Day' sessions which I attended in May 2007. This was a day long workshop discussing living with Hepatitis C which gave us tools to address living with infection; one of the discussions covered looking after yourself by implementing a balanced diet and performing regular exercise. I started going to yoga and found that it was helpful in dealing with stress as through this I learnt relaxation techniques that helped me to deal with the stresses of life.

58. With regard to giving up alcohol, we are living in a society where alcohol is linked to all social events and giving it up made me feel isolated, alienated from friends and society. People would ask why I would give

up alcohol, they thought I was a freak to give it up but when someone gives up smoking people are very encouraging and supportive. This pushed me more in the direction of yoga as it is more mindful and supportive of clean living. I felt that I fit in more in with the yogi community and this became my main source of social outlet.

Section 7. Financial Assistance

59. I recall that I found out about the fund online that I did receive payment from the Skipton Fund of £20,000 but I cannot recall specific dates.

60. I do recall that no one from my team at Leicester Royal Infirmary mentioned the Fund however it was discussed with me by my consultant when I was receiving treatment in Northampton.

61. I do not recall the application process but I recall needing to provide my medical notes. By this time the Manfield Orthopaedic Hospital in Northampton had closed down but I did not have any problems obtaining my notes and providing the Fund with the relevant information. However, I do know of people who have had problems.

Section 8. Other Issues

62. One of my main issues is tracing everybody who was infected. I do not know how many blood transfusions are given every year nor do I know how many people received a blood transfusion before 1991. It would not be an easy process to track everybody down and it worries me how many people are out there and do not know that they have contracted Hepatitis C.

63. Additionally, for me awareness is so important which is why I gave the interview for the magazine (**Exhibit WITN0082002**). It is so important to get tested and these days treatment is so accessible and the infection is curable.

64. It is good to know that this Inquiry is not a box ticking exercise being performed.

65. I present the following exhibits to accompany my statement:

Exhibit Number	**Description**
WITN0082002	Interview with She Magazine, February 2010
WITN0082003	Karampatou, Ha, Kondili, Bao, Sanchez Gonzalez and Villa (2018) '*Premature ovarian senescence and a high miscarriage rate impair fertility in women with HCV*' *Journal of Hepatology* Volume 68, 33-41

Statement of Truth

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

Signed GRO-C

Dated 22nd April 2019