

Witness Name: Christina Hendra

Statement No.: WITN0089001

Exhibits: WITN0089002 -

WITN0089004

Dated:

## INFECTED BLOOD INQUIRY

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### WRITTEN STATEMENT OF CHRISTINA HENDRA

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 13 May 2019.

I, Christina Hendra, will say as follows: -

#### Section 1. Introduction

1. My name is Christina Hendra. My date of birth is GRO-C 1969 and my address is known to the Inquiry. I am a mother to three children and a business owner. I live in Canada and have recently been granted Canadian citizenship.
2. I intend to speak about my life after contracting hepatitis C ("HCV") from a blood transfusion in the UK. In particular, the nature of my illness, how the illness affected me, the treatment I have received and the impact it has had and continues to have.
3. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement. The

Inquiry team has explained anonymity and I do not require any information to be kept private.

## **Section 2. How Infected**

4. I discovered that I had scoliosis when I was a teenager. Initially I found doctors dismissive of my condition and I recall attending a doctor's appointment one time and was told that I just needed to "stand up straight"; however, I already was standing as straight as I possibly could.
5. By the time I was diagnosed with scoliosis, I was told that it was too late for braces. When I was 18 years old I was informed by doctors that I required surgery. I was told that if I did not have this surgery I would end up in a wheelchair. I subsequently underwent two operations on my spine.
6. In October 1988, when I was 19 years old, I had my first operation. My dad had medical insurance so I went to a private hospital, Parkside Hospital in Wimbledon. I underwent the 'Harrington rod' procedure, which is when holes are drilled in your spine, and a metal rod is implanted.
7. Following this operation, I was in hospital for a month. I know that I received blood transfusions during this period, but I don't know how many transfusions I had or how much blood I received.
8. On 12 April 1995, I had a second operation at St Georges Hospital, London. This surgery was not as major as the first procedure in 1988, but resulted in partial removal of my ribs as well as the rod that was previously implanted, as that rod had broken due to metal fatigue.
9. I am unsure whether I had any transfusions as part of this operation. I was discharged from hospital on 25 April 1995.

10. When I was younger I travelled significantly so was not often in one place for long. I was living in Hong Kong when my mum phoned me to tell me about a letter that had been addressed to me from the National Blood Service ("NBS"). My mum had opened the letter and relayed to me that it was possible that I had been infected with hepatitis C (HCV).
11. I exhibit a copy of this letter received from Dr P E Hewitt, Lead Consultant in Transfusion Microbiology at the NBS dated 21 October 1996 as **WITN0089002**. The letter states, 'I am writing to you in relation to the blood transfusion you had in the Parkside Hospital, in October 1988. We have now discovered that the blood may have been carrying an infection known as hepatitis C virus which could have been passed on to you'. I was asked to attend a clinic so they could explain the situation further and take a blood sample from me for testing.
12. I had no idea what HCV was as I had never heard of it before. I had been working in Hong Kong for just over a year at this point but following the call from my mum I flew home to the UK.
13. On 12 November 1996 I underwent a blood test as requested. I then received my diagnosis by letter. I received a letter dated 25 November 1996 from the NBS which confirmed that my blood sample been tested for evidence of HCV and the result was positive. It was stated that my doctor had been advised that I should be referred to a liver specialist for further assessment and that my doctor had been given a list of specialists who would be willing to see me. I attach a copy of this letter as **WITN0089003**.
14. I then went to Brighton and Sussex Hospital ('BSUH') for my first appointment after my diagnosis. The appointment was on 8 November 2005. I was told that the only treatment available would take nine months, had a 20% success rate and that I would be ill for the entire treatment period. I decided not to go ahead with this treatment. I am unable to recall what the medication they were offering was called. I

didn't go ahead with the treatment because at the time I did not think that the infection was that serious a threat to my health, and also because the success rate was very low and the treatment would have made me very ill.

15. I still don't understand why I really needed the treatment and what would happen to me if I didn't have the treatment. All I remember is that I was told not to drink alcohol.

16. At this appointment I was not questioned about my lifestyle. I don't believe there was any doubt that the infection was caused by the transfusions I had in 1988. I'd never had transfusions before my spinal surgery. I have also never taken drugs in my life and have never had tattoos.

17. I have been told that the reason I became infected with HCV was because the blood I received was not screened in 1988/9. I was never told about the fact that high-risk people were donating blood.

### **Section 3. Other Infections**

18. I have not contracted any other infections, besides HCV, from having a blood transfusion. I don't recall being tested for HIV at the same time that I was tested for HCV, as I was informed there was not a connection between the two viruses. I have subsequently been tested for other infections such as HIV and the results have been negative.

19. My ex-husband and children have also been tested for HCV with their results being negative.

### **Section 4. Consent**

20. I do not recall being told about having to have blood transfusions as part of my spinal surgery. My mum may have been told, but I was an adult at the time, so I expect that I should have been told as well. As far as I can recall I wasn't aware of the need for a transfusion, but I most likely would not have declined it at the time, as I required the surgery.

21. I don't believe I have ever been tested without my knowledge.

### **Section 5. Impact**

#### **HCV treatment and physical impact**

22. Not too long following my diagnosis I moved back to Hong Kong for approximately half a year. When I moved back to the UK I attended BSUH every three months for a blood test until I immigrated to Canada. Every time I went back to BSUH they would give me an update on my condition and tried to encourage me to undergo the available treatment but I would always say 'no'.

23. In November 2007 I immigrated to Canada. I think that I was required to undergo a medical examination before I moved to Canada. I don't know if I was tested for hepatitis C as part of this medical examination.

24. Within half a year of moving to Canada I saw a HCV consultant and was informed if I didn't undergo treatment my condition would worsen. However, the treatment offered was the same as what was offered to me in the UK, which had a low success rate and you would feel ill for a period whilst taking it. I declined to go through with the treatment suggested.

25. For years I had no symptoms of HCV that I was aware of. About six to seven years ago I first noticed that I was more tired than usual. About four years ago I found this tiredness worsening, I was going to sleep all the time. I found it to be a different sort of tiredness that would just

overtake me and I would have a sudden, overwhelming desire to go to sleep. I would sleep every afternoon only waking up to pick up my children from school. I also put on a lot of weight, as the chronic fatigue I was experiencing meant I did not have the energy to do much, and I was not doing any exercise.

26. Along with chronic tiredness, I have also had memory problems and adrenal fatigue, which I have been suffering with for a few years. I have experienced brain fog and no energy. Even though my doctors were aware that I had HCV they had not made the connection with my symptoms of fatigue. I also experienced depression, stress and anxiety.
27. A letter dated 28 January 1999 states that a liver biopsy revealed that I had liver damage.
28. In Canada I wasn't required to attend hospital for a quarterly test like I was in the UK. I did attend a local doctor regularly for about six years, and would also attend my local hospital for fibroscans, which have shown the level of inflammation of my liver is elevated. The fibroscan showed that I was over F1, which indicates minimal scarring, and at the beginning of F2, which indicates that scarring has occurred and extends outside the liver area (significant fibrosis). The doctors state this is not cirrhosis.
29. In April 2018 I was prescribed Epclusa (otherwise known as Sofosbuvir or Velpatasvir). I was informed that Epclusa has a 97% success rate. I took one tablet a day for twelve weeks. Every province in Canada has its own health care so this treatment was paid for by Alberta Health Services. The medication was couriered to me; I would receive one month's batch at a time.
30. I was still experiencing the chronic fatigue as part of HCV. Some of the side-effects of the treatment included tummy upsets, anxiety and depression. I finished the treatment in August 2018 and then had to wait

three months to have a test. I was then told by doctors that the results showed as negative and that I am now clear from HCV.

31. I don't really know the current state of my liver but I have been told that the liver regenerates. I do not have to go back to hospital again for HCV.

32. For many years, I have been searching for answers for memory loss, fatigue and lack of energy. Due to being diagnosed with ADHD, I had various cognitive testing and have been diagnosed with cognitive impairment (MCI).

33. I had a brain scan in July 2019 which showed loss of brain cells and brain shrinkage, which is more common for someone much older than my years. This is confirmed with a poor score in cognitive impairment testing. The brain scan also showed that I have an acoustic neuroma, which has grown in the past year.

34. There are links between neurocognitive effects of the hepatitis C virus and cognitive impairment.

35. I am very sure that if I had not stopped drinking alcohol when I found out I had hepatitis C, it is unlikely I would be alive now.

#### Pregnancies

36. I have experienced difficulties with my pregnancies and childbirth. I am very sure that the blood transfusion it is likely to have attributed to the complications I experienced with my pregnancies, through the antibodies received.

37. In my first pregnancy I developed preeclampsia in the eighth month. I subsequently delivered my first son via emergency caesarean.

38. My second pregnancy was terrible ; I suffered from polyhydramnios and at three months I looked like I was eight months pregnant. I was confined

to bed rest and couldn't move very easily. My skin had stretched which was very painful. The medical professionals wouldn't let me deliver until I was 37 weeks so I went in for a planned caesarean as soon as I could. I ended up having an emergency caesarean

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40. In my third pregnancy I suffered from polyhydramnios in the second trimester. At around 28 weeks pregnant I had bad pain. I went to hospital and had some tests done, but was told there was nothing wrong. Something didn't feel right but I had another ultrasound booked in for the following week.

41. I attended this appointment when I was 29 weeks pregnant. I was taken to a room and told that there were complications. I was told to go straight to the labour ward where they started to do tracing and I was getting worried because it all sounded strange. The next thing I knew I was being rushed in to have an emergency caesarean. Devastatingly, my second son was born brain damaged and we had to turn off the 'life' support machine.



42. The doctors told me my antibodies had attacked him, starving him of oxygen, causing fetal anaemia; they said that my blood cells attacked him and starved him. Polyhydramnious can be present in conditions that cause foetal anaemia, such as isoimmunization (where the mother's immune system attacks the baby's red blood cells). I understand his cause of death was from anaemia. After my scan on the day that he passed away, the plan was for him to have blood transfusions in the womb, which is why I was told to go to the labour ward.
43. My fourth baby was within a year of giving birth to my second son. I felt that I really needed to have another baby after having lost my son. This time the hospital allowed me to deliver at just under 36 weeks by caesarean. It turns out I had a torn uterus.

#### Mental impact

44. I have experienced both depression and anxiety. It has taken me many years to recover from losing my son. Seven years ago, I received treatment in the form of antidepressants. I am still taking antidepressants to this day. I was taking sleeping tablets for a good few years but I am no longer taking these. Six years ago, I was prescribed anxiety medication but I didn't take them for very long as I was concerned that they were addictive.
45. When I lost my son I saw counsellors, a psychologist, and was having therapy that I sought myself, but which was free through the health service. I currently attend a local mental health hospital for therapy sessions.
46. At no time has psychological support been offered to me in relation to HCV.

#### Social, Family and Stigma

47. Socially, my HCV diagnosis meant that I had to stop drinking when I was living in Hong Kong. Prior to this, while I had been living in Hong Kong, I would drink quite regularly socially. I was definitely told that drinking would quicken cirrhosis. Following this, I would maybe have one drink a year and now I don't drink at all. Otherwise, I didn't want people to know that I had HCV as they might feel worried that they could catch it and avoid me.
48. When I met my husband, I had to tell him, 'by the way I have HCV', which is not something you really want to tell people. We also had to risk having children, as there was a small percentage that the HCV could be passed onto them.
49. I wouldn't really tell my friends or anyone about HCV. I didn't want people to know as they may feel that they could catch it and may avoid me. It wasn't like there was anything that people could see. I was under the impression that people didn't really know about HCV.
50. The day-to-day affect was that every time I cut myself and bled I would always quickly cover the blood so I didn't pass on hepatitis C to anyone. I was also conscious never to share my toothbrush.
51. One of the worst things about HCV is not having or not being able to obtain life insurance, so I do worry about the children should anything happen.
52. My life has been very stressful with not being able to obtain life insurance due to hepatitis C. Also, there was the worry that if no drug was developed with a good success rate I could get cirrhosis and need a liver transplant and die.
53. There was also the worry I felt from uncertainty, and I felt that I should hide it from people as they would not want to know me. I also felt that I should hide it from employers.

### Work and Education

54. When I first moved to Canada I wasn't working because I was looking after my young children. When my youngest daughter was one I had to go back to work and I really struggled with my memory around this time. I was working in an aviation administration and flight coordination role, authorising private flights and logistics. I found my job challenging, and I had to work longer hours to complete the work.

55. Three years ago, I set up my own shipping company and despite working from home, I struggled to get going and was sleeping every afternoon. I was so ambitious and driven but could not fight the fatigue. I had no energy and no motivation. I could not do all of the things that I wanted to do. I only have one client at the moment, but mentally I have struggled to find the time to fit in everything that I want to do. I definitely haven't achieved everything I have wanted to do career-wise.

56. Having HCV has not stopped me in respect of education. I went to university at age 30.

### Finance

57. I have found it so hard financially as I was tired and struggled so much to work. I am thankful that I haven't lost my house. At one point I was four months behind on paying the mortgage and I was selling belongings to get by.

### Section 6. Treatment/Care/Support

58. I think it is lucky that I found out about needing to undergo a test for HCV. By 1996 my parents had moved out of London to GRO-C I believe the next owner of our prior home must have forwarded the post to their new address quite quickly. I am just very appreciative that I found out about

my diagnosis when I did and was able to take actions to not worsen my condition, for example stopping drinking.

59. On 4 July 1997 I received another letter from the NBS in respect of my HCV infection. This letter explains the NBS's actions and their attempts made to contact me. This letter is attached as exhibit **WITN0089004**.

60. It is a worry to me that no one ever really explained the actual impact of HCV. No medical professional ever told me that you could get cirrhosis or die from HCV. I remember just being told that HCV may never affect me at all. I don't think the medical professionals really understood the impact of HCV.

61. I don't think that I was refused other treatment because of HCV in the UK or Canada. The only thing I am aware of is that I cannot donate blood.

#### **Section 7. Financial Assistance**

62. I received money from the Skipton Trust before my oldest son was born; I believe this must have been in 2002. I was in the UK at the time and received a payment of £20,000. I cannot recall exactly how I found out about the Skipton Trust but I believe I received a letter informing me about it.

63. I did not receive a second lump sum payment as this was only reserved for people who had cirrhosis, and fortunately my condition has never progressed to cirrhosis.

64. I also received a monthly payment from the Skipton Trust. Following the Skipton Trust transferring to the England Infected Blood Support Scheme ("EIBSS") I now receive £450 per month for the children. I have been informed that from July 2019 I will receive £28,000 per year.

65. I have found it so much work to try and obtain financial assistance. It takes me hours to complete all the forms. Skipton are very helpful over

the phone with questions, however, the application process is not simple and you have to be careful not to miss out any information.

66. I previously received a £250 top-up payment from the Caxton Foundation every month. I started receiving this in December 2015 because I was on a very low income and was not working. I was very fortunate to receive this payment as it started when I was really struggling. I also received a fuel allowance from the Caxton Foundation. I no longer receive these payments as I think they have been replaced by the EIBSS payments.

#### Section 8. Other Issues

67. I have made enquiries with IBB Solicitors in the past; however, I decided against pursuing any further action as I do not want undergo the stress of participating in litigation at this stage.

68. I want my story to be heard in order to help other people and I do hope that my statement assists in this.

#### Statement of Truth

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

Signed

GRO-C

Dated

28 JAN 2020