

Witness Name: Therese Young

Statement No.: WITN0044001

Exhibits: WITN0044002 –

WITN0044004

Dated: 13 October 2018

## **INFECTED BLOOD INQUIRY**

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### **WITNESS STATEMENT OF THERESE YOUNG**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 30 August 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Therese Young, will say as follows: -

#### **Introduction**

1a) My name is Therese Young. My date of birth and address are both known to the Inquiry. I am an infected person. I intend to speak about how I was infected with Hepatitis B and C during a blood transfusion in 1978. In particular, the nature of my illness, how the illness has affected me, the treatment received and the impact that this has had on my life.

#### **Infected Blood Inquiry**

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## How I was infected

- 2a) I was infected with Hepatitis B and C in January 1978 at the Chelsea Women's Hospital when I was transfused with 2 pints of infected blood which had been provided by the Queen Charlotte's Hospital. I exhibit a copy of my discharge notes with my statement which records my transfusion at **[WITN0044002]**. I was 40 years old at the time I was infected.
- 2b) I had originally been admitted to Chelsea Women's Hospital for Ventral Suspension surgery. Unfortunately, there was a complication and I developed a blood clot which resulted in me being taken back to theatre to have it removed. During that operation a drain was inserted, however this was incorrectly placed into an artery.
- 2c) The following day (which was a Saturday) I suffered a huge bleed and lost a lot of blood and it was necessary for me to return to theatre for a blood transfusion. There was no blood available at the Chelsea Women's Hospital and so the blood that I was given was delivered from Queen Charlotte's Hospital. In total, I was given 2 pints of blood.
- 2d) I was not told about any risks of a blood transfusion.
- 2e) I was diagnosed with Hepatitis C in May 2001. I had been feeling unwell for some time, in particular I had suffered with episodes of dizziness in 2000 which led me to consult with my GP. I had blood tests which showed that my platelets were low and further investigation was needed.
- 2f) Due to the long wait for further tests within the NHS I paid to have more tests and a liver biopsy privately at the Sloane Hospital. When I went back for a follow up appointment at the Sloane Hospital the Consultant told me that he had received results for two of three blood tests which were normal but he was waiting for the results of the third test.

2g) My blood had been sent to the Blackheath Hospital for testing and so the Consultant said that he would call me at home to let me know the results.

2h) That evening he telephoned me at home at 6:00pm. The first thing he asked me on the phone was "Therese, do you drink?" I explained to him that I wasn't a heavy drinker. In the moment, I forgot that I had a blood transfusion in 1978. He then said, "I am sorry to tell you that you have Hepatitis C". The phone call was only a few minutes and the consultant did not tell me what Hepatitis C was.

2i) Following my diagnosis, I went to see another consultant at Bromley Hospital. By coincidence, this was the same consultant that I had seen at the Sloane Hospital. It was decided that I would be referred on to Kings College Hospital which had the best liver clinic.

2j) I wasn't given very much information regarding Hepatitis C after my diagnosis, however, shortly afterwards my family and I attended a meeting in London to learn more about the disease and treatment, however, this left my family and I more confused.

2k) Everything that I have learned about Hepatitis C has been through books and picking up leaflets at the hospital. The doctors are always so busy that I don't really have time to ask questions. I educated myself about what to do.

### **Other Infections**

3a) I have no further comments to make on this issue.

### **Consent**

4a) I have no comments to make on the issue of consent.

## Impact

- 5a) After I was infected in 1978 I returned to my normal life (I didn't know that I had been infected at the time). I was a widow with young children to look after. However, it is clear now that Hepatitis C impacted on my ability to work. I worked for the Council in an old people's home, however, the Council retired me early (in 1987) because I wasn't well and could not do the heavy lifting which was needed for me to perform my job. At the time, my GP thought that I had arthritis and I would never have dreamed that I was unwell as a result of Hepatitis C. I had to go on sickness and social security benefit.
- 5b) Despite the fact that I was diagnosed with Hepatitis C in May 2001, I was not able to access any treatment until October 2001. My family wrote to my local MP, Eric Forth for assistance. Eric Forth wrote to Michael Kerin who was the Chief Executive of Bexley, Bromley and Greenwich Health Authority. The letter was then passed on to Bromley Primary Care Trust who confirmed that they had granted funding for my treatment to Kings Healthcare NHS Trust. I exhibit copies of the correspondence as **[WITN0044003]**.
- 5c) I began being treated for Hepatitis C with Interferon and Ribavirin in 2002 following my diagnosis.
- 5d) The Interferon was a 40 week course, but they stopped it at 38 weeks because of the side effects which were terrible. I felt like it was killing me, I couldn't eat or go out.
- 5e) I have Parkinson's disease as a result of being treated with Interferon and exhibit my discharge notice from Kings College Hospital dated 8 January which records that I have "IFN-Parkinsonism" at **[WITN0044004]**. Interferon has also damaged my heart, the left branch is blocked and I have had a heart attack.

5f) Between 2002 and 2009 I was having ultrasounds every six months because my liver was full of cysts and cirrhotic; In 2014 one of the cysts changed and I was diagnosed with cancer and Hepatitis B which I must have contracted during the transfusion in 1978. I was treated for cancer and had to take Lamivudine tablets because treating cancer with chemotherapy can encourage the virus to grow in patients with Hepatitis B.

5g) A liver biopsy at Kings College Hospital in September 2014 confirmed that a cyst had become cancerous.

5h) On 28 September 2014 I was taken into hospital with upper right quadrant pain. Initially I was treated with pain killers which masked the fact that I had suffered from a liver bleed. Eventually I had a scan which revealed that I had a bleed on my liver. I had encephalopathy and liver failure and was in a coma. I was discharged from hospital on that occasion on 19 October 2014.

5i) In 2015, I was given another treatment for Hepatitis C. It didn't work for the first three months and when I saw the Consultant they said that I should stay on the treatment for another six months. This involved me having injections in my stomach twice a week at the GP's surgery, At the end of those six months, I collapsed and I found out that I was anaemic and required an iron transfusion and neutropenic.

5j) In 2015, I was informed that I was free of the Hepatitis C virus. I had to wait another three months for more blood tests which were negative for Hepatitis C and another three months after that which also showed that I was free of the virus. Although this is good news, it's too late as I have already developed liver cancer and am living with the severe side-effects of Interferon and Ribavirin.

5k) Between December 2014 and November 2016 I started TACE treatment for

liver cancer. I have had 7 cycles of this treatment which has had some effect, initially the tumour was shrinking, but it stopped working and the tumour began to grow again.

5l) On the 13 February 2017 I started Sorafenib, however this was suspended on 8 May 2018. In June 2018 I started a course of Regorafenib, however, this had to be stopped because the side effects were so severe. I am not currently receiving any treatment for cancer. I had been due to start another trial but I have recently developed high potassium levels (7.1) which has led to another hospital stay, and I cannot be part of the trial. I have recently been told that I am terminally ill.

5m) I don't have a life because I am constantly attending doctor and hospital appointments. I cannot always go to my GP's surgery because there is a risk that I will contract another illness and so my GP will consult with by phone; I can't go out whilst I am waiting for these calls.

5n) In addition to the physical impact there is also any emotional one. Since 2002 people have asked me whether I am angry or whether I am going to sue but I have never done that, I just have to get on with it, but I can't make plans anymore.

5o) More recently, I have been feeling very bad for my husband and think that he must be fed up with everything that has happened I feel sorry for him because we can't go anywhere, he is retired now and could have a good life but my illnesses have stopped that.

### **Treatment/Care/Support**

6a) I have never had counselling or been offered it. I have always managed on my own.

### **Financial Issues**

7a) I have received money from the Skipton fund, although I was not provided the information on how to obtain it. One of my friends, Shirley had seen a story on the television regarding financial support for people who had received infected blood and telephoned me to tell me that I would be able to apply for financial support. My daughter, Anna obtained the forms for me and my oldest daughter completed them. The forms asked for my treating doctors to confirm that I had Hepatitis C and so I gave them to my Consultant who completed the forms which I then collected and sent off. I was initially given a payment of £20,000.

7b) After about 6 months the Skipton Fund said that if an infected person's Hepatitis C had developed to Stage 2 (this is when the liver becomes cirrhotic) a payment of £25 000 would be made. I applied for, and was granted this in 2004.

7c) After this either Anna or I received letters from the Skipton Fund which said that I was entitled to a monthly payment (this later became quarterly) but I did not ask for anything.

7d) I then moved house and it didn't occur to me to inform the fund that I had moved. About 2 years later, Anna got an email from Michael Fish who informed her that the Skipton Fund were looking for me as I was entitled to further payment. I received a further lump sum which was back-dated.

7e) I now get financial support from the EIBSS scheme. I am paid £1500 per month, It used to be less (£3000 per quarter). In the last few years I have been told that I am entitled to fuel payment. Other than that there is nothing else that I am aware of.

### **Statement of Truth**

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

Signed \_\_\_\_\_ **GRO-C** \_\_\_\_\_

Dated 13-10-2018