



Witness Name: Leslie James Thorpe  
Statement No: WITN0003001  
Exhibits: None  
Dated: 19<sup>th</sup> October 2018

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF LESLIE JAMES THORPE

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 04 September 2018. I adopt the paragraph numbering in the Rule 9 request for ease of reference.

I, Leslie James Thorpe, will say as follows: -

#### Introduction

1. My name is Leslie Thorpe. My date of birth is GRO-C 1948 and my address is known to the Inquiry. I am a married man and I live with my wife. I have two sons and five grandchildren, four boys and one girl. We are and always have been a very close family. I intend to speak about my life and how I came to be infected with the Hepatitis C Virus (HCV).
- 1.1. In particular, I will go into detail on how the contamination has impacted on my general health and well being. How the illness has affected my relationship with my wife and other close members of my family. My eventual diagnosis and the treatment I have received. I have been asked if I am currently legally represented, the answer is no. I am content for my statement to be taken by the investigators from the Inquiry.

#### How Infected

2. I cannot really pinpoint the exact occasion when I was infected with Hepatitis C. As a young boy I always had trouble with bleeding, especially at the dentist. I had to have one tooth removed and the wound would not stop bleeding. If I cut myself it would just bleed and

bleed. At the age of about ten I was diagnosed as suffering from Haemophilia A, from then onwards I received Factor 8 and blood transfusions as and when they were required. In the 1960's I was also in a car crash and suffered a head wound and some internal bleeding. I think I received blood on that occasion. Both my brother and uncle bled to death, they too suffered from Haemophilia.

### Background

- 2.1. From a very young age I was interested in the building trade. So much so that in my young adulthood I set up my own very successful building company restoring listed properties, Victorian railway stations and the like. I received a national award for my building work. As a Haemophiliac I had to be very careful working in this trade and on site, I did have the occasional scrape but I managed very well. I was a workaholic, seven days a week.
- 2.2. If I cut myself at work I would have to go straight to hospital, this was normally the Sussex County. In the 1970's, I remember cutting my hand quite badly and they had to give me Factor 8.
- 2.3. I can remember attending the Sussex County for blood tests, the medical staff would prick my ear and make it bleed. The blood would be caught on blotting paper and they had a way to establish if it was clotting or not.
- 2.4. In the late 1970's early 1980's I began to feel unwell. I was in my late twenties. I couldn't understand why I felt so bad, especially as I always kept myself healthy. I didn't smoke or drink; I made sure I ate a good balanced diet.
- 2.5. I had really low energy levels and I was constantly tired. The only way I can describe this is for you to imagine the worst type of flu, this feeling was constant. This was not how a fit active person in his twenties should be feeling.
- 2.6. I decided to go to my Doctor to find out what was going on. He told me that I was jaundiced and arranged for a blood test to be done.
- 2.7. I attended the surgery for the result and he told me that I had Hepatitis C. No advice was provided to me on how to manage this virus and or the health implications for my family and me. I ended up receiving a leaflet and that was about it.
- 2.8. Over the years I became very weak and grim; the virus really knocked me for six. Both mentally and physically, I lost all my get up and go, all my motivation. I became a very ill man.

- 2.9. Eventually, I cannot remember the exact date, I was sent to see a liver specialist.
- 2.10. The liver specialist was at Brighton General Hospital. He told me that the Hepatitis C had really damaged my liver. He also told me that due to the fact that I was a Haemophiliac they couldn't do much to help me. The consultant actually said to me "you've got about 6 months maybe a year" just like that. Well you can imagine the impact this news had on my family.
- 2.11. I have always been very pragmatic and have never shied away from facing up to what had to be done. I went to see my solicitor and informed him of the prognosis. I transferred my business into my eldest son's name and made sure all my accounts were in order and then sat back and waited to die.
- 2.12. Sometime in 1994, I cannot be more precise; I received a telephone call from Kings College Hospital London. I was informed that a surgeon in Philadelphia USA had performed the first successful liver operation on a Haemophiliac patient. Kings suggested to me that I should consider the transplant. I agreed. To be honest I didn't think I was going to survive; my attitude was that I hadn't got long left and if the medical profession could learn from operating on me then all the better.
- 2.13. Eventually a suitable match came through and I was told to get to Kings College hospital as quickly as I could.
- 2.14. I must admit I did not think I was going to make it through the operation, I remember coming around from the operation and was surprised, was this it I thought, am I in heaven. I was quite surprised that I had actually woken up. My son was stroking my arm and I couldn't feel it, he looked like a hologram, it was all very surreal.
- 2.15. I was one of the first Haemophiliac's to be successfully operated on; I remember my bed being surrounded by Doctors.
- 2.16. Even though the operation was a success I was told that the transplant would only last 8 to 10 years and I would be on medication for the rest of my life.
- 2.17. Notwithstanding the success of the operation and the added time I have had with my wife and family the transplant operation has caused me other health problems. I have had relapses, acute stomach problems, such as sickness and diarrhoea. Three years ago I lost in the region of two to three stone in weight.

- 2.18. I have had several exploratory endoscopies to establish what was going on, unfortunately with a negative result.

### Other Infections

3. As far as I am aware I have no other infections. With the amount of blood tests I have been subjected to over the years I'm sure I would have been told if I had contracted some other infections.

### Consent

4. I am not sure who would have provided consent when I was a young boy; I guess one of my parents. As an adult, I would have provided my consent. If I had not received the Factor 8 or the transfusions I would have bled to death like my brother and uncle.

### Impact

5. As I have stated previously, I was a very successful builder. I managed my Haemophilia and this did not stop me from working hard, having a normal family life etc. It was extremely rare for me to have to take a day off.
- 5.1. After the Hepatitis C virus infected me, things changed. I have already described the lack of energy, the listlessness I felt, the constant feeling of being unwell, and very depressed and nauseous
- 5.2. I have already mentioned the damage to my liver and my subsequent liver transplant.
- 5.3. I have also had problems with my kidneys, after examination it transpired that I have lost 75% function in each kidney, this is as a result of the drugs I have been on and my liver not working properly. The long-term immune suppressants and Hepatitis C causing kidney damage.
- 5.4. I have also been informed that I have an enlarged spleen.
- 5.5. I have been a patient in the Sussex County Hospital. In one year I had over 50 treatments where they replaced my fluids, 3 litres in and three litres out. All because of the infection. This treatment was to clean my plasma of all impurities. I had to have a biopsy before a fistula was inserted, one temporary which was inserted into my chest to get my

blood into the main vein, one of these was permanent to insert the fistula (2013) to facilitate giving plasma exchange (Plasmapheresis)

- 5.6. The biggest impact has been on my family life, the unknowing of how I might infect my family. [GRO-B]  
 [GRO-B] Emotionally, very stressful for both my wife and I. I was petrified about getting an infection [GRO-B]  
 [GRO-B]  
 [GRO-B]

5.7. One of the other consequences of the drugs I have been on has resulted in me having brittle bones. Sometime ago, I was working and I tripped over and hurt my back, the pain was agonising and I went to the hospital. They did the tests and I was told that I had broken my back at the 3<sup>rd</sup> or 4<sup>th</sup> vertebrae. I was told that I could have an operation to repair it, however research showed that the success rate was only a 50-50. I was not prepared to take the risk; I did not want to end up in a wheel chair. I manage the pain.

5.8. I also have problems with my bowel regularity, sometimes I do not go for 3 or 4 days, on other days I spend all the time sitting on the toilet. Also, after my liver transplant I have no sensation when I urinate, I cannot feel a thing.

5.9. Even though I received a new liver in 1994, the Hepatitis C virus has also damaged this. I have developed Cirrhosis.

5.10. Historically my eyesight was very good. Since my liver Operation it has deteriorated.

5.11. My liver didn't cope with the acids and damaged my stomach lining. This affected the veins and caused internal bleeding. I had to undergo a procedure called "Bandings" This is where the veins, (varices) have to be tied off via an endoscopy.

5.12. There have been times when I have felt very low. Extremely weak and unable to walk. My family would always make sure someone was with me when I ventured out, just in case I collapsed. My dog has been a great companion and she has seen me through many dark hours, she seems to understand when I am feeling unwell or down

5.13. Stigma has also been a real issue. In the early years when I was in hospital the nurses tended to the other patients first.

5.14. I was treated at arms length. Different towels. As I have said already, I wouldn't go near the kids; I was scared of passing the virus on to them.

- 5.15. I have lived with the constant mental side effects of not knowing how long I have got left. It's been 24 years since my transplant. This is very difficult for my family and me.

Treatment/Care/Support

6. After my liver transplant the Hepatitis C stayed within my body, my liver once again started to be affected. To prevent further damage it was decided that I should go on a programme to try and eradicate the virus from my body.
- 6.1. Three to four years ago I commenced the treatment. I took Ribavirin pills and self-administered Interferon injections. The treatment lasted for approximately eight months. The side effects were horrible, sickness, no energy, no appetite, skin problems.
- 6.2. The Specialist informed me that the treatment had not worked, the Virus was still present. I decided to have another go, again without success.
- 6.3. The Specialist informed me that the reason for the failure was due to the fact that I was a 'Non Responder' Apparently I have a very unusual strain of Hepatitis C. I couldn't come to terms with the fact that the treatment had failed as I was now feeling so much better. The consultant said it was because I had been so ill before.
- 6.4. I was then prescribed Sofosbuvir and Ledipasvir 400/90Mg respectively, one tablet a day and Ribavirin, 200Mg. Amazingly this treatment worked and I am now clear of Hepatitis C.
- 6.5. I am retested for the virus every six months. My last check up was two months ago.
- 6.6. As far as my treatment is concerned I have been fortunate, I have never encountered any obstacles, I have never had a problem with the NHS.
- 6.7. My dentists have always been good, thoughtful and fully aware of my condition. Yes they wear gloves but they do that for everyone.
- 6.8. I have never been offered any form of counselling. Although now I think this should be compulsory.

**Financial Assistance**

- 7. I first heard that compensation was available when I was receiving treatment at Kings College Hospital. I cannot remember who told me. I decided to apply; I think this was in September 2004. From memory the process was quite detailed but manageable.
- 7.1. On 7<sup>th</sup> October 2004, I was awarded a payment of £20K. This was received with mixed feelings. I felt really bad about claiming the compensation against the NHS. Factor 8 was a lifesaver. I gave £5K to each of my grandchildren. I now know the money was not taken from the NHS but is from the Government.
- 7.2. In 2004, I received another payment from the Skipton Trust. This was for the sum of £25K. Since then I have also received a monthly payment of £1,500.

**Other Issues**

- 8. I want whoever is taking charge of all the results of this inquiry to understand the suffering we have been through. Not only the recipients of infected blood but also our wives, partners etc. For example, when I die my wife will not get the monthly payments. Why not? This has affected her life immensely, it is very wrong that the payments will not continue. My working life was cut short; the opportunity I had to ensure my family had financial security was taken away from me. I did have four houses; due to my illness I could not manage them. My wife should be given financial help when I am gone.
- 8.1. I don't want to give oral evidence.
- 8.2. I consent to my statement being used at the hearings if required, that said, I do not want the identity of my family made known to the general public.

**Statement of Truth**

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

Signed

GRO-B

Dated

19-10-18.