

Witness Name: Huw Michael Thomas

Statement No.: WITN0023 - 001

Dated: 11 December 2018

**INFECTED BLOOD INQUIRY**

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**WRITTEN STATEMENT OF HUW MICHAEL THOMAS**

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I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 11 December 2018.

I, Huw Thomas, will say as follows: -

**Section 1. Introduction**

1. My name is Huw Michael Thomas. My date of birth and address are known to the Inquiry. I am a married man with two children (one daughter and one son). I live with my wife and daughter in Swansea, Wales. I am retired. I was a motor mechanic by trade.
2. When I was four years old I was involved in an accident. I was hit by a lorry and had severe injuries. I needed a skin graft on my leg. In the late 1940's skin grafting was in its infancy. Whilst I recovered from my injuries, the skin graft didn't take as it should and instead of growing with my leg it was stretched with the result that if an object hit it, it would split. Over the years this became a problem.

3. Moreover, the healing process to recover from knocks or bumps was extremely long. For example, if I injured my leg I would develop bruising which would slowly rise to the surface before forming a scab. The scab would then stay on my leg until the skin underneath had completely healed. This process could take up to 6 months. Up until I was twelve years old, this meant I would have to go to the hospital frequently.
4. My father was a SRN nurse who worked for the NHS and in the Royal Navy during the war. One of his regular patients had discovered their eczema had dramatically improved after using a product called Mercurochrome. My father thought the product might benefit me too. It was – my symptoms improved significantly. I continued to use the product to manage my symptoms.
5. In 1976, when I was 31/32 years old the skin graft started to fail and I went to see my GP. I was referred to a specialist (surgeon) who recommended that I have the skin graft replaced. The surgeon then carried out the operation, however, put the new graft in the wrong location – it was to the side of my injury rather than directly over it. I pointed this out to him and he took this very negatively – he was angry and annoyed. The surgeon then refused to speak to me directly. I have never had this rectified.
6. After the operation, I was given two bags of blood (which I now believe was infected).
7. I intend to speak about my infection with non-A, non-B Hepatitis now known as Hepatitis C (HCV), cirrhosis of my liver and my subsequent transplant. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on me, my family and our lives together.

## **Section 2. How Infected**

8. It is my belief that I was infected with HCV in June 1976 at St Lawrence Hospital in Chepstow by receiving a contaminated blood transfusion following an operation to replace a skin graft.

### **Background**

9. I remember the summer of 1976 being very hot – the roof of the operating theatre at the hospital was being sprayed with water to cool it.
10. I believe it was the hot temperature that led doctors to give me a blood transfusion. I was told it was to aid my recovery and assist the skin graft to take hold. This was the only information I was given. From memory, I do not remember signing or consenting to anything formally. Nor was I provided with any information around the risks of the transfusion.
11. In 1986/1987 I started to experience flu like symptoms. I assumed it was a virus that would pass. It didn't and the symptoms persisted. I was feeling fatigued and a degree under all the time. My energy levels were low and I was constantly feeling tired. I hadn't suffered from headaches previously but I developed a faint headache during the day.
12. Over time new symptoms appeared. I had severe itching – I would scratch all the time. It felt like I had a worm was under my skin. I then started to get blisters. They were filled with clear fluid.
13. I knew something was not right and went to see the GP. The doctor diagnosed that I had some sort of allergy but didn't know what it could be. I was prescribed various medications to address the issue. I remember telling the doctor that I had no known allergies. None of the treatments worked and my symptoms persisted.

14. I was frustrated and went to seek a second opinion. The doctor suspected I may have diabetes and ran checks. I remember having five separate tests. All of them bar the fifth one came back negative. The last test was inconclusive and it was interpreted as a 'maybe'. As a precaution I was prescribed Gliclazide – a drug to manage diabetes.
15. I was on this medication for months. During this period my blood sugar was checked. My glucose levels never seemed to vary that much. Meanwhile my original symptoms persisted and I decided to stop this treatment.
16. I went to see my GP again. This time he suggested I do a liver function test and sent me to Singleton hospital in Swansea. A specialist saw me: Dr Kingham. After performing the test I was told there was a problem with my liver. At that stage I remember being told that it was not serious but they wanted to diagnose the underlying cause. Dr Kingham probed into my drinking habits. I was never a heavy drinker. I used to enjoy a few pints when I played darts or whilst I watched the rugby. I would say perhaps 12 pints throughout the week. I have never taken recreational drugs either orally, smoked or injected. Despite probing, they could not diagnose my condition so they continued to monitor me.
17. During one consultation I remember having a discussion about Hepatitis A and B. I subsequently had these tests carried out and both came back negative. I was then told that there was a new test that was being developed for Non-A, Non-B Hepatitis – Hepatitis C (HCV). I did this test and it was positive.
18. After the test I received a letter to go and see Dr Kingham. I remember sitting down and seeing him. Dr Kingham confirmed I had HCV. He told me it was a virus that attacks the liver. Other than this, I do not recollect receiving any information on how to manage the condition nor help me understand it. I remember one doctor telling me that I could pass on HCV by mixing bodily fluids e.g. saliva through kissing. This resulted in a great

deal of alarm and anxiety as I feared I could have passed it on. I now know this is not true.

19. Dr Kingham traced my HCV infection back to when I had my skin graft operation and the subsequent blood transfusion back in 1976 at St Lawrence hospital. I recall asking him how I could cure it. I got a very blunt reply – there was no cure “you’re either going to die or you’ll need a liver transplant”. That said, I trusted him and felt reassured that he would look after me. The monitoring continued.

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

20. I do not believe I have contracted any other infections as a result of HCV. That said, the medications that I take on a daily basis have started to affect my left eye. I have started to lose vision. This should be checked every couple of years but so far I have only been invited to two appointments.

### **Section 4. Consent**

21. At the time, it is difficult for me to say whether I had been given the full information before being tested or treated. Information was limited. In hindsight, I feel I should have been provided with more information especially in relation to the risks and side effects of treatment.
22. I was not told about the source of my blood transfusion until 2008. I was furious when I found out it was from prisoners and drug users in the United States.

### **Section 5. Impact**

23. The realisation of being infected with HCV was unbelievable. Everything seemed different. The sounds of the birds were more apparent. The sky and colours were much more vivid – the sun was brighter. In hindsight, I

was in a complete state of shock. It was like being handed a death sentence. I felt that I would be dying in a few years.

24. Amongst all the negative thoughts I had slight optimism too. I thought maybe just maybe that they would find a cure at some point in the future. People used to say cancer was a death sentence but some people had successfully been treated. Shortly after my diagnosis, I remember going to a friend's house. I told him about my HCV and how I had been handed a death sentence. At that stage no one really knew what it was and whether it was contagious. This made me worry and be anxious in everyday life. Eventually I just got on with life.
25. I remember an event that affected me a lot though. A member of my rugby club who was an undertaker found out I had HCV and said to me "Ah, 5ft 7 and 13 stone – call me when you need me" and he handed me his business card. This made me feel really upset and I struggled to be in his company at future events. I eventually stopped going to the club.

#### *First round of treatment*

26. Around 1990, Dr Kingham suggested I start treatment for HCV. He recommended I go on Interferon. I had to administer an injection at least twice a day for three months. I had blood samples taken regularly during this period and it didn't change my situation. The medication then stopped.

#### *Liver growth and Transplant*

27. By 1998/1999 the HCV had caused growths on my liver. From memory they were about 12mm in size. I was referred to the Queen Elizabeth Hospital in Birmingham. They carried out a series of blood tests and scans. The doctors determined that I needed to have the growths removed. I was due to have surgery on 31 December 1999 but just before surgery the doctors determined the growths were too aggressive and they

couldn't operate. They determined the only solution was to have a liver transplant.

28. I had biopsies and various tests. So many that I cannot remember what was what. I remember being in hospital for around a week. As a family we had to go and see a liver coordinator and I recall seeing a psychiatrist who wanted to make sure I was mentally stable. Both my family and I were informed about the risks of the surgery, the possibility of complications and what to expect and prepare for.
29. I felt I had no choice but to go ahead with surgery even though I felt it was experimental at the time. I would not receive a complete liver. It was separated into two lobes and given to two patients. That said, for me it was a question of whether I lived or died. I was given a buzzer to take home and told when the buzzer went off I would need to phone the hospital immediately.
30. I remember there being two lists – a priority one and one where the patient had a bit more time. I was placed on the priority list due to the seriousness of my condition, which made me feel as if my diagnosis / situation was critical. After discussing this with the transplant co-ordinator in the Queen Elisabeth Hospital, I arrived home about 8:30 in the evening on the 17/01/2000. At 12:30 am the buzzer that I had been given by the transplant co-ordinator went off and I was told to return to the hospital as a matter of urgency. I arrived there at about 3:30 am. I was not transported in an ambulance as I drove there myself. I remember being told prior to the transplant that I would be discharged from the hospital 2 to 3 weeks after surgery. Nothing prepared me for how long it took to recover.
31. I was told that although they had a liver it did not guarantee a transplant because they still needed to check whether it and my arteries match. In my case one of them didn't match exactly but it was something they could resolve by putting a stent into the artery after the procedure if necessary.

After monitoring my blood supply, the medical team concluded that I would not require a stent as the problem had resolved itself. Other than this the operation went smoothly.

### *Recovery after transplant*

32. After the surgery I would be checked on a daily basis to see how the blood was flowing to my liver. I remember the first few days were fantastic – everything was going well even though I was on lots of drugs. On the 6th day, however, things changed. My body started to reject the liver and I went into a coma for about a day.
33. I remember being very upset when I came round from the coma. After about 2 months, a doctor told me my new liver wasn't working as it should and that they had used every drug available to no avail. I was also advised to get my house in order as it was likely I would die in the very near future. I started to lose my appetite and for a month after I wasn't eating properly. I began to eat peanuts to increase my protein intake. In hindsight, I felt the hospital were not doing enough to take care of me.
34. I remember speaking to a doctor I believe his name was [GRO-D] about my lack of appetite. I recall telling Dr [GRO-D] at least 6-8 times that I couldn't eat, but I do not believe any action was taken. I should have seen a nutritionist, but this did not happen. When I finally saw one they mentioned that they should have seen me earlier and had no idea how I had slipped through the net.
35. By March 2000 all I had eaten was a bowl of cereal and half a boiled egg. I became very weak and frail. I then stopped eating entirely and as a result I was being fed through a tube inserted into my stomach. I remember in early April, the doctors suggested I go home for the long weekend. I remember thinking they were letting me pass away at home. Before the operation I weighed 13 stone. I weighed 8.5 stone when I was



sent home. I was very, very weak when I left. My wife had to wash and care for me. This was very stressful for both of us.

36. I continued to be fed via a tube at home. One of my neighbours popped round to see me. She said she was glad to see me back home but after seeing me was overcome with emotion and ran out of the house crying. She couldn't compose herself to come back in.
37. This was a turning point for me. I had had enough. I thought I was dying and could no longer cope. I pulled out my feeding tubes. My wife then suggested I try some food and prepared some hors d'oeuvres and tasty morsels. I remember having one and then after an hour having another one. I was incredibly weak. My bowels were not used to solid food and after a few days as they started to work again I experienced severe pain. At the time I thought it was my liver failing but in hindsight it was the bowels. They were starting to function again. I gradually increased my food intake, my bowels adjusted and the pain I was experiencing subdued.
38. After two weeks of consuming food I started to feel a bit better. By the third week I was able to have a small meal.
39. I then had an incident where I spewed out a cup full of dried blood. I was taken by ambulance to Queen Mary hospital in Birmingham. They examined me and concluded it was left over blood from the operation. Neither they nor I could understand why it had taken months for this to happen.
40. I was going back and forth to the hospital twice a week since being allowed to go home. I had to pay all the costs of going back and forth to Birmingham. It was very costly. My wife had to book into a local B&B in Birmingham most of the time I was in hospital.

41. During this time, I was under the care of a HCV specialist called Mr Mutimer. I was still very ill and I did not know what was wrong. Roughly 10 months after my transplant my new liver started to work. I remember it being a huge sigh of relief. After 18 months I was feeling a lot better and I had put on a bit of weight and was feeling stronger.

### *Career*

42. By now I was 57 and started to feel better. I wanted to see if I could work again as I was around £63,000 in debt. I had the experience but I struggled to find a position. Once they knew my background I was asked to see a doctor before the job was offered. If it progressed I would usually get declined because I wouldn't be insured. Others just rejected or never got back to me as soon as I mentioned my HCV.
43. I had previously worked abroad in mechanical engineering through agencies. I began to explore these options again but I was advised by a doctor not to go abroad because there was a risk of exotic bugs. My mortgage and debt was piling up. I had no sick pay or company pensions to fall back on. I ended up selling my house to move into a new one to free up some equity. The new house was nice but in a derelict state but it was all we could afford at the time.

### *Second round treatment*

44. In 2002 Birmingham hospital were concerned about the amount of damage that the HCV was causing my new liver. They told me my new liver would have the same fate as my old one if I did not address the HCV by treating it. I remember them telling me they had formulated a new treatment (Pegylated Interferon) – it was experimental and the hospital asked me whether I wanted to go on it.
45. Naturally I was eager to start treatment. I didn't want to risk anything happening to my new liver. I was, however, quite apprehensive. This

wasn't helped when a German doctor asked me what strength of the drug I wanted. There were three options, small, medium and large. I remember asking for the large one because I wanted to ensure I was cured. I felt the patient choosing the dose was crazy and I still do not understand this.

46. Once I started treatment the side effects were severe. I do not recall being told about any side effects. My personality changed massively. I was nasty, moody and very irritable. It was so bad that at one point my wife almost divorced me. On reflection, how she put up with me I will never know.
47. I remember constantly feeling tired. I had severe aches in the upper part of my body. It was all very uncomfortable. It was twelve months of hell.
48. I was one of thirteen patients that started the treatment. The side effects were so extreme that nine patients dropped out soon after starting the course and then another two later on. I believe only two of us managed to complete the twelve-month course.
49. I was clear of HCV in 2003 but it was only officially confirmed in 2005. I remember being told in a face-to-face consultation and I believe a subsequent letter.
50. Even though I am now clear of HCV, I was told that transplanted livers typically last between 10 – 12 years. My liver has lasted 19 years, so I feel like I'm living on borrowed time. I live in constant fear that my liver might be rejected and I don't know how long it will last. The only option should my liver fail is to have another transplant. Given my current circumstances I believe the chances of another liver are slim. I, therefore, feel like I have the Sword of Damocles hanging over me. I'm often anxious but I don't like to talk about it because it will affect my family. There are side effects to the medication I am currently taking, which I do experience but these are not significant.

## *Lifestyle*

51. I have had to make significant lifestyle changes to accommodate my condition. I currently take around 160 tablets every week. I pre-prepare the pills that I need to take at the start of the week. Every morning I spend about 20 minutes taking tablets and checking my blood pressure. When my family sees the amount of medication I take it brings the whole situation home to them. I do not like to talk about it with them. The less I talk about it, the more its out of their minds. I feel all of the drugs have now caused my memory to fade.
52. Other than that, I always get the flu jab when it's available, avoid crowds and confined spaces. It is very frustrating but I know I have to do it as my life depends on it.
53. One of the possible side effects of the transplant is diabetes. Prior to 2000 I took no medication. Currently I am taking numerous tablets and I have to take two types of insulin twice a day. One of them I take three to four times a day.
54. My quality of life has suffered massively. When I was working I was earning a very good salary. I would have expected to be living in LLangennith (an upmarket part of the city). We lost our £400,000 home and at least that amount again of salary (about 10 years). My children have lost all of that through the negligence of the NHS and the Government at the time of my blood transfusion, and since.
55. I believe the Government should compensate all the victims of this scandal, with a minimum of £250,000 lump sum and the monthly payment increased to £2500 under the same conditions they are at present. The monthly payments should continue in full to the spouse/partner after the demise of the victim. On the demise of the spouse/partner, the children should receive equal shares of the monthly payments for at least 20 years.

56. David Cameron stated in parliament when he was prime minister that all victims should be compensated by means of a meaningful and worthwhile package. It would be a refreshing change to see the right thing being done by the Government.
57. More importantly, I was expecting to give my children some money – to give them a leg up in their lives. I feel that I have deprived my children of a decent legacy.
58. Whilst my quality of life has improved since being clear of HCV I still cannot enjoy holidays abroad because of the dangers of exotic bugs. I live in constant fear of catching things whenever I am abroad which is rare these days.
59. I have had a few holidays in the UK. I went to Shrewsbury for a holiday in October this year for my 50th wedding anniversary. Other than that, I acquired a touring caravan when I bought my current home. I used this a few times to do trips to Cornwall and the Lake District. My wife did not really enjoy these trips and after about five or six ventures we ended up selling the caravan. Holidays for me have been few and far between.

### *Stigma*

60. I do not like to share information about my condition with my friends or family. I keep most things to myself – I feel embarrassed. When I first found out I had HCV, however, I was concerned about the nurses. I didn't know whether I could pass it on. I received confusing information. This caused me a lot of concern and worry. I used to be upfront that I had HCV when going for routine blood tests for awareness and to ensure the medical staff could exercise caution. I felt judged. They immediately thought I must be a drug user.

61. When I went to an appointment I did not want to engage in much conversation with the receptionist about why I was there. Other patients often overheard which caused me a lot of embarrassment and I felt belittled. This whole situation made me feel isolated.
62. I feel that the NHS should give victims of this scandal 'priority medical cards'. The effects of HCV aggravate other health problems. Luckily I didn't have any but I know people who have so I think there should be a priority service for these individuals.
63. I tend not to go out much these days. I used to play darts, pool and also squash up until I was around 52 but these activities have now lost their appeal.
64. I guess I feel bitter because of what happened. If the blood had been treated this scandal would never have happened. I believe this blood was known to be infected and it was a way of forcing the Government into a position where they had to fund research into HCV.

#### **Section 6. Treatment/Care/Support**

65. I do not feel I was given any support to deal with my condition. The aftercare was pretty poor.
66. The investigator has made me aware of the British Red Cross support that is available and he has provided me with a card with their contact details and I will consider this option.

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

67. In 2004/2005 after reading an article in the paper my aunt phoned me saying that people who had been part of this scandal were being offered financial assistance. She gave me a telephone number to ring. On my first phone call I was informed I could not claim financial compensation, as

HCV was not known about prior to 1988. I believe, this must have been a Government directive. I subsequently phoned again and I filled in various forms from Skipton – some of which I forwarded to Dr Kingham to send off. Other than the first phone call issue, it was relatively straightforward.

68. I then received a stage 1 payment of £25,000 from Skipton. After they realised I had received a transplant they offered me another £25,000. I am not sure whether this is a stage 2 payment. In 2006/2007 I then received a further £20,000.
69. I currently receive a monthly payment of £1540. I believe this was around £1250 when it started. I feel this is wholly inadequate.
70. Prior to my aunt letting me know about the financial assistance that was available no one ever mentioned anything. There were multiple opportunities but I was not offered or told about anything. I feel the government should have been more proactive in giving compensation to the victims of this scandal.

### **Section 8. Other Issues**

71. I feel that anybody who was knowingly involved in this scandal should be held accountable for his or her actions but I am not seeking personal vengeance.
72. Over the years I have written to the government several times outlining the consequences of blood contamination for me and my family but I have had little or no response. I wrote to my MP and whilst they acknowledged the letter he did not act on it because I believe he was promoted to a health authority role and there would have been a conflict of interests.
73. For the first time, I have some hope that the victims will be listened to as a result of the inquiry. That said, I feel the inquiry is far too late. It should have been conducted over 20 years ago. I believe the inquiry should

consist of two parts. Firstly, why this was allowed to happen and who took this decision; and secondly there should be a review of the financial arrangements.

74. This contamination scandal should never have happened. I would like to know why the blood was not treated? Going back to the 1940's, medical professionals stated that they were concerned about the number of diseases being passed on through blood transfusions. It has become apparent since then that the HIV and HCV viruses die on contact with air or heat – why was this not done? As the Government is ultimately responsible they have an obligation to do the right thing.

#### Hospitals

- I contracted HCV in St Lawrence Hospital in Chepstow
- I discovered I had HCV in Singleton Hospital in Swansea
- I had my liver transplant and aftercare at Queen Elizabeth Hospital in Birmingham.
- My current GP is Professor Phil Matthews at GRO-C  
GRO-C

#### Statement of Truth

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

Signed GRO-C

Dated 20 - 1 - 19.