

Witness Name: Thomas Galanis

Statement No.: WITN0955001

Exhibits: WITN0955002 - 007

Dated: 13th September 2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF THOMAS GALANIS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 29 August 2019.

I, Thomas Galanis, will say as follows: -

Section 1. Introduction

1. My name is Thomas Galanis. My date of birth is GRO-C 1982 and my address is known to the Inquiry. I am a marketing consultant.
2. I intend to speak about my experience of Hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment I received and the impact it had on me, my family, and our lives together.

Section 2. How Infected

3. I was infected with Hepatitis C when I underwent surgery to repair the ventricular septal defect with which I was born.

4. I underwent this operation, commonly known as open heart surgery, on 30 April 1986 at The Harley Street Clinic. I was three years old.
5. The Harley Street Clinic (located on Weymouth Street in London) was one of the leading private hospitals in the world particularly when it came to heart surgery. I was seen by Dr Jane Somerville and Dr Marc De Leval who were known as some of the best heart specialists in the country.
6. The first three documents produced as exhibits (**WITN0955002 – 004**) that follow this statement, evidence the operation that I underwent, its success and the names of the surgeons.
7. After the operation, my parents were told that the operation had gone very well. They were told that they should bring me for an annual check-up at the hospital but I would not need any other medical attention.
8. I went for these annual check-ups until I was sixteen. At that appointment, I was told that I need not attend any further annual check-ups, and that I could live a “normal life”. At no point at these check-ups was Hepatitis C raised.
9. Throughout my life, I have suffered from fatigue and muscle and joint pain. From when I was a child, it has been difficult for me to recover from physical exercise. My body would ache for days after a football practice.
10. In mid-September 2018, I experienced extreme joint and muscle pain. It felt like I could not get out of bed and my body was failing. I thought I had done damage to my body without knowing how.
11. I went to the GP who told me that my symptoms were not normal. She recommended blood tests. I had three or four vials of blood taken.
12. The results of the blood tests showed that I had a high iron count. The GP explained that this may indicate that I have haemochromatosis.

13. I was referred to a private haematologist, Sara Trompeter, who sent me for further blood tests.
14. On 16 October 2018, I received a call from the haematologist, Ms Trompeter. At the time, I was on a business trip in Lisbon. She told me that while the results of the blood tests had shown that I was clear of haemochromatosis, I had Hepatitis C.
15. It was a shock for me to find out this way, especially at my age – I was thirty five years old at the time.
16. I had no idea what Hepatitis C was or how I may have contracted it. Thankfully, I was able to have a long call with the haematologist who explained the disease to me. I am aware of the privilege of this position. I do not believe that I would have had this opportunity were I not able to afford private medical care.
17. The haematologist went through the common causes of the disease. She asked me whether I had used intravenous drugs, had any tattoos, had homosexual sex, or shared razors or toothbrushes with anyone. The answer to all of these questions was “no”.
18. The haematologist’s last question was whether I had ever had a blood transfusion. I responded that I did not think that I had, but I told her about the open heart surgery I underwent in 1986.
19. Dr Trompeter suggested that I come in for an appointment when I was back in London, which I did. She referred me to a cardiologist for a scan and also to discuss the likelihood of my contracting Hepatitis C as a result of my open heart surgery.
20. I had the scan, and thankfully there were no problems with my heart. The cardiologist made some enquiries with his colleagues and advised me that it was very likely that I had received blood or blood products at the time of the surgery as part of a routine cardiopulmonary bypass.

21. I was referred to a hepatologist, Dr Suri, for an assessment of the damage to my liver. I was incredibly anxious during the fibroscan.
22. I was told that I have moderate fibrosis – an abnormally large amount of scar tissue in the liver – and that I had been living with some degree of liver disease for thirty three years.
23. Dr Suri identified that I had Hepatitis C genotype 1b. On this basis, he recommended that I undergo treatment with Zepatier, which I began in early January 2019 and continued for the requisite three months.
24. I had a blood test in June or July this year and am told that I have cleared the virus, but a further test in September is due to confirm this.
25. After my diagnosis, I tried to obtain my medical records from The Harley Street Clinic in a letter dated 21 January 2019. It was important to me to try to find out whether I had received blood or blood products during my heart surgery.
26. I also requested my GP records and while they contain the surgeon's report and subsequent reports from the Consultant Cardiologist, there is no record of blood use or transfusion.
27. After I received no response to my first letter, I sent a second letter to Mr Michael Neeb, CEO of HCA Healthcare, dated 25th March 2019.
28. This prompted an internal investigation at Harley Street Clinic into whether there was any record of my receiving blood products during my surgery in 1986, or failing the discovery of any records, what probability there was of having received blood products during the surgery. The investigation was lead by Ms Christine Hague, Head of Adult Clinical Services.
29. On 5 April 2019, I received a letter from Clare Sullivan, Deputy Chief Executive Officer at The Harley Street Clinic. It confirmed that while the hospital no longer held health records for me, there existed a perfusion

chart for my surgery that confirmed that 1000mls of blood, supplied by the NHS, was used to prime the bypass machine (theatre pump) of which some blood would have been delivered through my body during the surgery. This was confirmed by Mr Stuart Bailey, Chief Perfusionist at The Harley Street Clinic – see **WITN0955005**.

30. The letter continued. I was told that there was no record of the unit number of the blood used to prime the instruments – see **WITN0955006**.

31. In a letter dated 30 April 2019 to Clare Sullivan, Deputy CEO at The Harley Street Clinic, I asked for a copy of the perfusion chart to be sent to me, but I have not received it, nor have I received a response to my request, nor indeed my letter.

Section 3. Other Infections

32. I do not believe that I have received any infection or infections other than HIV, HCV and HBV as a result of being given infected blood or blood products.

33. I am unsure of whether I have been tested for Hepatitis B. It is possible that I was tested for all variants of Hepatitis prior to being diagnosed with Hepatitis C.

34. I have had an HIV test in the past and I am HIV negative.

Section 4. Consent

35. I do not believe that I have been treated or tested without my knowledge, consent, or for the purposes of research.

Section 5. Impact

36. The impact that Hepatitis C has had on my life is difficult to determine given that I have had it since I was three years old. I do not know a life without it and it is therefore difficult to know what is attributable to the disease and what I would have suffered from had I not contracted Hepatitis C.

37. I am aware of the danger of attributing all of the bad parts of one's life to the disease. I try my best not to do this.

38. From a physical point of view, I have always struggled with fatigue.

39. When I was a teenager, I was absolutely passionate about sport. I was fairly talented but I used to really battle to recover from exercise. My body would ache, and I would struggle with stiffness and joint pain for a good few days.

40. I would often feel like vomiting after a football practice.

41. *This deterred me from playing as much sport as I wanted to. I think that the effort that physical exercise demanded of me was too much.*

42. Eventually I stopped exercising. I thought at the time that I was just unfit and a bit lazy.

43. I have always had injuries and have struggled with my feet, ankles and lower back. For the last twelve years, I have been treated by an osteopath for my back.

44. I have always sighed when I sit down. People joke about it even. I have felt old for a long time.

45. From an educational point of view, it is difficult to assess how Hepatitis C affected me. I was always average academically in high school.

46. Again, I was thought of as rather lazy and last minute. It was therefore a shock to everyone, including myself, when I received straight As in my A levels.
47. I was asked by my school whether I wanted to consider going to either Oxford or Cambridge. I did not. I think I wanted to manage my own expectations and appreciated that while I had the ability, I may not have the capability.
48. I went to university at the University of Leeds where I did an undergraduate degree in history and then a Master's degree in Advertising.
49. I do wonder sometimes whether I would have been a better student and obtained better results had I not been so fatigued at school. These are some of the "what ifs..." that my illness has left me with.
50. I think that my professional life has suffered a lot from the fatigue that I believe was caused by the Hepatitis C that I was living with.
51. I work for myself and I have not been able to grow my businesses as quickly as I planned to. Prior to my treatment, I felt that I was in a big rut professionally.
52. For most of my life, I was not working as well as I can, and this definitely affected my businesses.
53. The industry in which I work requires a lot of client engagement, socialising and interacting. This is also what I am good at. But it took a huge toll on me physically and psychologically.
54. Before my treatment, I felt constantly overwhelmed. It was as if my life was stacked full of problems, things to do, and people to speak to. I felt that I could not function effectively.

55. During my treatment, I did not travel for work as I usually do. I focussed on getting well during that time.
56. This was an important time for me. Because I was always so exhausted from the lack of energy I suffered from, combined with the commitment needed to fulfil my job, I feel that I was an absent parent, or at least not as present I would have liked to have been. The time of my treatment was a time for me to be with my family and focus on what matters to me.
57. I feel guilty that I have not been the parent that I want to be. It is something that I have been trying to work on since my treatment. I have never felt that I had the time or energy to go on a family holiday or to spend real quality time with my family.
58. My wife has had to shoulder the majority of the parental responsibilities. I was always too tired to do night feeds, or to play with my two daughters for long periods of time.
59. I was also really bad at switching off after a day of work. Because I never felt that I had achieved what I wanted to in any given day, I would be reading bedtime stories while reading work emails. I felt guilty that I was neither being the father I wanted to be, nor providing to the extent I wanted to.
60. Since being treated for Hepatitis C, I feel that my ability to be effective is much better. I do not feel so overwhelmed and I feel that I have more energy to do the things that I need to do.
61. I used to feel that I could not think clearly and my brain felt 'foggy'. This improved gradually over the time of my treatment.
62. The biggest change that I noticed after my treatment was my ability to think clearly.

63. This makes me wonder what I would have been able to achieve and what my life would have been like had I never been infected with Hepatitis C.
64. Since finishing my treatment, my work has been going better. I have not had the dramatic energy boost that some people have after treatment because of the extent of the damage to my liver.
65. I no longer drink alcohol as a result of the damage to my liver. This is difficult in the “thirsty” industry in which I work. My job requires me to attend many dinners, nights out, and conferences – it’s the way that deals and sales work in my industry.
66. It is difficult to have to explain why I no longer drink. It is also sometimes harder to enjoy the events and functions without the crutch of alcohol.
67. I have been fairly open about having Hepatitis C since I was diagnosed. I have written a blog post on my website about my experience with Hepatitis C. The post follows this statement as an exhibit labelled **WITN0955007**.
68. I struggle with the idea of people pitying me. I do not want to be defined by Hepatitis C, or known as “the guy that went through that horrible thing”.
69. I have fortunately not experienced much stigma. Sometimes people make silly jokes when I tell them about how I contracted Hepatitis C, but it is never really serious.
70. I have been a lot freer talking about it than my wife has. She has to deal with the “playground gossip” and I think it has been difficult as Hepatitis can be associated with risky behaviour.

71. My friends have been supportive but it has been difficult to socialise in the same way as I used to. I can no longer meet my friends for a pint at the pub.
72. Moreover, it is difficult for me to talk about the emotional aspects of having Hepatitis C with my friends. That is something I have had to learn to do. It can be a lonely experience.
73. Particularly difficult for me is dealing with what my life would have been like had I been healthy. I have moments of regret when I wonder whether my life was supposed to turn out the way that it has.
74. These thoughts bring with them feelings of guilt that I can even contemplate regretting the incredibly privileged, full, wonderful life that I have been blessed with.
75. These emotions are what I am grateful to have counselling for. The three or four months of psychotherapy that I have been attending have helped me to deal with the complex feelings that have arisen from finding out about my infection and unravelling its impact on my life.

Section 6. Treatment/Care/Support

76. As I have stated, I was prescribed a twelve-week course of Zepatier through University College London Hospital. I waited six weeks to begin treatment. I started the one-pill-a-day treatment in early January 2019.
77. There were no real side effects of the treatment. As I have already stated, I was told earlier this year that I have cleared Hepatitis C.
78. I see a therapist which I pay for privately. I wish that everyone could receive the psychological support and treatment that I have received. It has really improved my ability to deal with the illness and to move forward with my life. I feel a lot better for it.

79. I have not had anyone from the NHS offer me any form of support or counselling.

Section 7. Financial Assistance

80. I have applied to EIBSS and my application was approved in July 2019.

81. I received a £20 000 once-off. I also received £3000 in backdated payments, and will continue to receive £1500 every month in perpetuity.

82. The application was not particularly easy or seamless. I had some trouble correcting a mistake that my hepatologist made on the lengthy forms.

83. I was grateful for the money. It felt a little like the admission of guilt that I craved, but then I began to wonder what the money meant, and whether it was enough.

84. It felt strange to be receiving money once I was rid of the disease. I would have preferred to have been alerted to the fact that I may have had Hepatitis C at an early stage rather than be receiving money at this late stage.

Section 8. Other Issues

85. I decided to contact the Inquiry because I had been following the oral hearings and noted that nobody had dealt with contaminated blood received from private hospitals. It struck me that part of the story that needs to be told is that the problem was not restricted to the NHS.

86. Moreover, even the best private medical care that money could buy did not prevent people from receiving contaminated blood. I want it to be known that the fortunes of privilege cannot shield people from Hepatitis

C. Nobody can consider themselves “above” being contaminated through infected blood.

87. Most important for me is for people to realise that the category of people at risk of having contracted contaminated blood is far broader than haemophiliacs, drug users, homosexual men, and people who have received blood transfusions.

88. People who had invasive surgery in the 1970s, 1980s, and 1990s – such as myself – need to realise that they are at risk of having received contaminated blood. To my knowledge, priming theatre pumps with blood was standard practice at that time.

89. I believe that there should be a public health warning, perhaps in the form of a television campaign, making people aware that if they had invasive surgery within a certain time period, they are advised to have a Hepatitis C test.

90. I am passionate about raising awareness so that people get tested and receive treatment before it is too late. The lack of awareness is highly problematic to my mind. I want this to change.

91. I feel that the medical profession should also be better educated about Hepatitis C and the people at risk of having contracted it. My GP was unaware that my symptoms pointed to a possible Hepatitis C infection. This, I believe, is not an acceptable level of knowledge.

92. The fact that I was never contacted as part of a look-back exercise is horrifying to me. It should not be the case that one requires a large amount of resources, time and research skills to identify that one should be tested, and then to find out about the illness. I feel that I would not have found out about my infection had I not had the privileges that I do.

Statement of Truth

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

Signed

GRO-C

Dated 13th September 2019

