

Witness Name: Celia Bartalis

Statement No.: WITN0305001

Exhibits: **NIL**

Dated: 28/04/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF CELIA BARTALIS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 31 January 2019.

I, Celia Bartalis, will say as follows: -

Section 1. Introduction

1. My name is Celia Bartalis. My date of birth is GRO-C 1950 and my address is known to the Inquiry. I have been married to my husband, Mike, for approximately 39 years and I work part-time in sales administration. Within this statement, I intend to speak about my Hepatitis C Virus ("HCV") infection. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my husband and our lives together.

Section 2. How Infected

2. In 1967 (at the age of 17), I was diagnosed with severe colitis. I was very unwell at the time of this diagnosis and I weighed approximately six stones (38 kilograms).

3. My colitis was well managed for a number of years, however in 1976, I attended Luton and Dunstable Hospital ("Luton and Dunstable") following a particularly bad inflammation. I remained at Luton and Dunstable for approximately three weeks and during that time, I received four pints worth of blood transfusions. I was seen by my regular doctor, Dr [GRO-D], during my stay at Luton and Dunstable and I don't believe that I was given any blood products other than the transfusions.
4. Following the treatment that I received at Luton and Dunstable, I did not receive any information about the blood transfusions, nor did I receive any indication that the blood was infected. I had assumed that everything was fine as I trusted the hospital and had no reason to question the treatment that I had received.
5. After I had recovered from my treatment, I continued to have regular blood tests (every six to twelve months) in order to monitor the condition of my colitis.
6. Following a routine blood test in 2004, I received a telephone call asking me to return to the hospital to have a follow up blood test. This was out of the ordinary, so I returned to Luton and Dunstable to have the additional blood test. I was subsequently invited back to the hospital to meet with Dr [GRO-D], who informed me that I had tested positive for HCV. Despite the fact that I underwent regular blood testing from the age of 17, nearly 30 years passed before I was notified of my HCV infection.
7. When Dr [GRO-D] informed me of my HCV infection, I received very little information. My husband, Mike, was present when I was informed and we both left that meeting not really knowing anything about HCV. We had heard about what it was, but we thought that it was generally limited to drug users and people with tattoos. Mike has tattoos and was initially concerned that he could have been the one who gave me HCV. Mike wasn't offered any support or testing from Dr [GRO-D], we had to follow this up ourselves at a later date. In any event, we were offered no information about health precautions, no assistance and no counselling from Dr [GRO-D]. We were

entirely unsatisfied with the adequacy of information and support offered to us by Dr [GRO-D] and the NHS.

8. Despite being informed that I had HCV, I was offered no explanation of how I came to be infected. It was not until I heard about the Skipton Fund in 2004 that I became aware of the likelihood of my illness being caused by infected blood.

Section 3. Other Infections

9. I do not believe that I have any other infection that has arisen from the use of infected blood or blood products, other than HCV.
10. In the past, I have suffered from Blepharitis (inflammation and soreness of the eyelids), however I do not believe that this is connected to the HCV infection.

Section 4. Consent

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

Section 5. Impact

12. The mental and physical effects of having HCV and the associated treatments that I endured have impacted heavily not only on my life, but Mike's as well.
13. Mike has been incredibly supportive of me and has been by my side every step of the way. He takes time off work to attend every medical appointment with me and I would not have been able to administer my treatments for HCV without his help.

14. When I am at home, I experience a real lack of energy. Some nights I go to bed at 6:30pm because I am just too exhausted to do anything. We spent a weekend at Stowe to celebrate one of my significant birthdays, but I couldn't enjoy my time there as I did not have the energy to walk around and take it all in. My infection took the pleasure out of what was otherwise an opportunity for relaxation.
15. Our social life suffered immensely when I was diagnosed with HCV. We used to attend the local bowls club every night, but I just cannot do that anymore as I do not have the energy. We have lost friends as a result of this, and we have also lost friends solely because I have HCV. One particular couple that we were very close friends with completely changed when we told them I had HCV. We had told them with the hope that they would be more understanding (particularly as the man has Multiple Sclerosis), however we drifted apart very soon afterwards.
16. I have decided to remain quite secretive about my diagnosis, with the exception of informing my close family and my employer. My family was very supportive, although I do not see them very often as they live some distance away from us. Mike and I stay in touch with one of my brothers and he has been a great support to both of us. My employer was also understanding; however, my colleagues are generally unaware.
17. From a practical perspective, I have to be constantly aware of any possibility of infecting others. If I cut my finger, I would instantly think about not getting my blood anywhere – I am acutely conscious of it. If Mike bled for any reason, I get worried that he could be exposed to infection. There are times when I feel like a leper.
18. I am also conscious of the physical impact and the way I look. If I am simply heading down the road, I'm constantly aware of my appearance. I often wonder what I would look like if I were to have my teeth fixed, as they are not as strong or healthy as they were before my treatment. I have recently undergone a course of dental treatment which has resulted in the removal of almost all my teeth and being fitted with dentures.

19. In June or July of 2017, I was told by a specialist nurse at Luton and Dunstable (Theresa) that I had chronic liver cirrhosis. This was devastating for both Mike and I. We were somewhat aware of the consequences of a chronic diagnosis, but we did not receive much information about it. We had a look on the internet and we began getting quite concerned about what my quality of life would be like from that point forward. We began questioning everything, particularly about whether I should be drinking, how long would I live for and what kind of treatment I would have to undertake.
20. In August 2017 – about six weeks after being told I had chronic liver cirrhosis – I received a letter from Luton and Dunstable. The purpose of the letter was to inform me that I had been mis-diagnosed and that I did not have chronic liver cirrhosis. The hospital also sent me a letter confirming this (and providing an apology) on 10 August 2017, a copy of which I have shown to the Inquiry. I attended the hospital shortly after receiving that letter, where I met with a doctor (I do not recall his name) who apologised immediately and said words to the effect of “the first thing that I need to say to you is that I am sorry you were told that you had chronic cirrhosis of the liver”. Mike and I felt incredibly relieved after hearing this.
21. On the way home from the hospital, we celebrated by going out for a nice lunch together and then went to the bowls club at night where we shouted everyone a drink. We had told our close friends at the bowls club about the cirrhosis diagnosis, so they were equally relieved to hear the news. Our friends had witnessed the physical and emotional impact that the diagnosis had on both of us over that period and they knew how much this information meant to us.
22. It goes without saying that being improperly diagnosed with chronic liver cirrhosis had a highly distressing impact on our lives. For six weeks, Mike and I carried the burden of not knowing what our future would hold, what options were available to us or how long I would have to live.

Section 6. Treatment/Care/Support

23. After being diagnosed with HCV in 2004, I wasn't offered any assistance or treatment from the NHS. I took it upon myself to start looking at treatment options. I utilised the BUPA private healthcare system offered by my employer to get in touch with King's College Hospital ("King's College"), where I was seen by Dr O'Grady.
24. Dr O'Grady was very good, he sat down with us for about an hour and explained everything we need to know. He told us that there were five stages of HCV, that I was at stage three and because it had taken me 30 years to get to this stage, I would likely die of old age before reaching stage five. In a sense, he was implying that I still had the opportunity to live somewhat of a normal life.
25. I had my first liver biopsy with Dr [GRO-D] at Spire Harpenden Private Hospital in 2007. After I received the results, I asked Dr [GRO-D] when I should return for a follow up biopsy and his response was "how many bloody liver biopsies do you want?"
26. After the results of my first liver biopsy, I had a further biopsy with Dr [GRO-D] at Luton and Dunstable hospital where we began to discuss the treatment options that were available. Dr [GRO-D] was reluctant to recommend the treatment programs that were available at the time, as there was only a 55% success rate and there was a strong possibility that the treatment would inflame my colitis dramatically. We were happy to pay for the treatment, however Dr [GRO-D]'s view remained that the probability of success was not proportionate to the likelihood of the treatment causing severe problems with my colitis. The second biopsy I mention above was in fact followed by a third biopsy, as it was discovered they had not taken enough material to undertake the various tests.
27. I didn't hear anything from the NHS for ten years. I assumed this was because we had proceeded with BUPA. In any event, my GP (Dr Turner)

was happy that I had gone to King's College. I couldn't fault Dr Turner, he was always very supportive.

28. The first contact I had with the NHS following my diagnosis was in 2014, when new treatments for HCV were beginning to surface. I decided to undertake my first round of treatment at Luton and Dunstable, where I was actually the first person to be treated with Interferon and Ribavirin. The treatment was undertaken at home and I would attend the hospital once every two weeks for a check-up.
29. The first round of treatment lasted for approximately twelve weeks and involved taking tablets twice daily and injections once a week on a Thursday. I was very fortunate to have Mike at home, as I struggled to administer the injections. Mike is a Type 2 diabetic, so he was used to having regular injections and was able to help me with mine. I could not have done it without him.
30. When I commenced the first round of treatment, I started losing some of my hair, I had chronic fatigue, I lost teeth, the bone structure in my mouth shifted and I had terrible thrush. In addition I developed terrible eczema over my whole body. This was particularly bad around my eyes. There were some days where I felt very emotional and depressed. I shed many tears and there was one Saturday in particular where I just couldn't stop myself from crying all morning.
31. Despite all this, I continued to work (as best I could). I had informed my employer and one of my colleagues that I was undergoing treatment, however I did not want anyone else to know as I did not want to draw attention to it.
32. I used to walk to work, however once the treatments started I had to get a taxi there and back each day, which proved to be a considerable expense. I struggled with my concentration levels, couldn't do basic things such as lifting paperwork and I had to arrange for a colleague to assist me with preparing the tea in the mornings as it involved walking up and down two

flights of stairs. I was often very stressed when I returned home after a day at work.

33. The first treatment was unsuccessful. I was informed by Opal, my nurse at Luton and Dunstable that the treatment had not worked. Mike and I could not speak more highly of Opal. She conducted herself professionally and compassionately at all times, and was always willing to answer any questions that we had. Opal had warned us prior to undergoing the treatment of the possible side effects and worse case scenarios. She would regularly give me a call to update me with results during the treatment. On one occasion, Opal rang while I was at work and she told me that if I didn't take time off work I would end up collapsing and having to go back to hospital. She was always looking out for my best interests, she prepared us very well and was absolutely brilliant throughout the duration of the treatment.
34. At one stage, Opal attempted to set up a regular support group for people that had been infected with HCV. We went to the first meeting and met with a number of people, where we would discuss various matters and spend time with other people living through the same difficult circumstances as ourselves. Unfortunately, this was the only session of its kind as Opal could not secure the support needed to run the group on a regular basis.
35. Approximately three months after finishing the first round of treatment, I commenced a second round which lasted about twelve months. The actual treatment still used Interferon and Ribavirin, but involved a longer dose. This time the injections really got to me. Whilst I was undertaking the second round of treatment, Mike had a stroke and had to spend some time in hospital recovering. This meant that I didn't have him at home to help me with my injections, so I had to go to the hospital to get a nurse to administer the injections for me.
36. The second treatment was also unsuccessful. I was initially told that it had cleared, however subsequent testing confirmed that the treatment had not worked.

37. In May 2016, I commenced a third round of treatment using Sofosbuvir, Daclatasvir and Ribavirin for approximately three months. This was the course of treatment that Dr O'Grady had previously recommended as it did not involve Interferon. I undertook this treatment through the NHS at Luton and Dunstable, however this time I was assigned a new specialist nurse, Theresa.
38. Theresa was not nice at all and I considered her to have a terrible approach. I would attend the hospital every two weeks and see Theresa to have tests done on the functionality of my liver (these tests showed us that the drugs were working as we could see the levels going down). It was Theresa that told me I had chronic liver cirrhosis after my third round of treatment and despite the hospital subsequently notifying me that this diagnosis was incorrect, we heard absolutely nothing from Theresa herself.
39. Despite the mis-diagnosis, the third round of treatment successfully cleared me of HCV. I do not recall experiencing any side effects during the third round of treatment.
40. Follow up testing and ultrasounds have revealed that my liver no longer shows increased echogenicity, my spleen appears normal and there has been no detection of HCV for over twelve months since completing the third round of treatment. A recent fibroscan has revealed my condition is what they describe as 'borderline' and have now been signed off by the hospital
41. I do not recall being denied access to other types of medical treatment (e.g. dental work) as a result of my infection. When I first went to the dentist after finding out I had HCV I was treated exactly the same as any other time I had been there.

Section 7. Financial Assistance

42. I was first told about the Skipton Fund in 2004, by a friend of mine whose father had received a pay-out after contracting HCV from an infected blood

transfusion. The NHS had never mentioned the Skipton Fund (or any other fund for that matter).

43. We applied for the paperwork from the Skipton Fund and I received a letter which suggested that I may be eligible to receive some financial assistance. The letter enclosed an application form which needed to be signed by a doctor before it could be sent back to the Skipton Fund.
44. I filled out the application form and took it to Dr [GRO-D] to have it signed. Dr [GRO-D] was very irate about having to complete the application form and when we received the signed form back in the post, it had been torn up and stuck back together with tape.
45. Once we received the form in the post, we sent the application to the Skipton Fund along with my medical records and proof that I had received the blood transfusions. We were not required to provide any further information and I then received a one-off payment of £20,000 in 2005. I am not aware of any preconditions that were associated with this payment and I just assumed that they were paying us to stay quiet about their mistakes – as if it was essentially “hush money”.
46. After we received the one-off payment, nothing else was really mentioned and we just continued on living independently. I have not applied for any more money from the Skipton Fund, as I do not believe that I am entitled to any more. If you progress to stage five or get cirrhosis of the liver, you can get an extra £25,000, however I was diagnosed as stage three. As I am cleared now, there is no avenue to apply for another payment.
47. I do not think that a one-off payment of £20,000 was sufficient compensation for the damage that this has caused to my life. I lost three years of my life undertaking treatment, which involved countless trips to the hospital. For every appointment that we went to, Mike would lose a day of income, we would incur parking fees or costs for train travel and we would have to pay for other incidentals that come with being away from home for

48. I currently receive a monthly payment of approximately £200 and an annual heating allowance of £519 from the EIBSS, which I have received for approximately two years.

49. I do not feel that Mike was offered the support that he should have had. I think that they should have tested Mike as soon as I was diagnosed with HCV, but they did not even discuss testing him. Mike immediately assumed that he had HCV as well, and he even thought that he was the one who passed it on to me as he had tattoos. He had to go to his own physician to be tested and thankfully, he did not test positive for HCV. The impact of my infection extends largely into Mike's life and this has not been accounted for by the NHS – they have let us both down.

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

Dated 28/4/2019.

