Witness Name: Mr Jason Ward
Statement No.: WITN1992001
Exhibits: 0
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WITNESS STATEMENT OF
MR JASON WARD
INFECTED BLOOD INQUIRY

Section 1: Introduction

1. My name is Jason Ward. My date of birth and address are known to the Inquiry.

2. I work part time as a psychotherapist.

3. I have a 20 year old son who attends university in Leeds and I support him financially.

Section 2: How Infected

4. On the 8th July 1985, at the age of 25 I was admitted to Farnborough Hospital, Farnborough Kent BR6 8ND, for a cholecystectomy procedure under the care of Mr Higton. Post operatively my haemoglobin dropped from 14 to 9.5 and I was transfused with three units of whole blood. Farnborough Hospital no longer exists but it is now under the effective control of Kings College Hospital, NHS Foundation Trust. My records from Farnborough Hospital cannot be found and there is nothing in the records that I do have providing details about the blood received.

5. During the period 1986 to 2005 I experienced aching joints, aching muscles, fatigue

and flu-like symptoms on a regular basis. In the first three months of 2005 my symptoms deteriorated, and I experienced a continuing fever, fatigue and muscle and joint pains. I was also starting to experience some episodes of itching in my legs and nausea with occasional vomiting.

6. I was unable to work on a full-time basis during this period, and my capacity while at work was also reduced.

7. I visited my GP surgery; Islingwood Road Surgery, 79 Islingword Rd, Brighton BN2 9SL around May 2005 and spoke with my GP Dr Eadie. Dr Eadie decided that I should have some blood tests. She telephoned me two weeks later and informed me that regrettably I had tested positive for Hepatitis C.

8. I was given no information about the infection at that time; however, I was directed to the Royal Sussex County Hospital where I made an appointment to be seen at the digestive diseases department. My experiences of treatment at this hospital was extremely poor; I was not seen by a consultant and after the failure of the treatment I had at the hospital, when I was told that there was nothing more that could be done for me, I was told that I should adopt a positive attitude to the disease (see below). I was given no information about possible risks to others and no access to counselling. I was very low at this point and it felt like I had been given a death sentence.

Section 3: Other infections

9. I believe that I have not received any other infection other than Hepatitis C.

Section 4: Consent

10. I believe that I received the blood transfusion without my consent, without my knowledge and without being given any, adequate or full information in relation to the blood transfusion.

11. I do not believe that I was treated for the purposes of research.

Section 5: Impact

12. I was referred by Dr Eadie to the digestive diseases department at the Royal Sussex County Hospital and was seen by one of the junior nurses. I was never seen by a consultant while I was treated there. I subsequently had a painful liver biopsy that was performed by a junior doctor who lost the sample within ten minutes. I then had to undergo an immediate second biopsy of my liver. The results from this biopsy showed a moderate amount of liver damage with scarring throughout my liver.

13. I was treated in 2006 for 24 weeks with interferon and ribavirin treatment which was quite brutal. This process was very distressing, I felt very low during this period. The process of treatment itself had many unpleasant side effects such as: hair loss; weight loss; fatigue; confusion; depression; memory loss. I spent most of this period bed-bound, alone and isolated. My short term memory was so badly affected that I could not remember why I had walked into a different room in my house and I found this very upsetting. I often had to write down first what task I wanted to do and take the notes with me around the house, so that when I arrived in a different part of the house I could work out what I wanted to achieve.

14. I believe that I experienced an emotional breakdown at this time as my reactions to everyday things were unpredictable, for example when I went to the local shops I would just burst into tears when paying for the goods, or when talking to someone I would again just breakdown and start crying. This was anxiety provoking as I didn't understand what was happening to me emotionally or psychologically. My mother kindly paid for me to see a private psychiatrist at the Priory Hospital Southampton and I was given a sedative medication to help me regulate my mood and thinking. I was told by the consultant that my brain was struggling to cope with all the toxins from the treatment drugs and from my poor liver functioning.

15. Those closest to me struggled to witness the deterioration in my appearance as I

had lost so much weight and most of my hair had fallen out, they were clearly very frightened, they were unsure about how to support me. I did not see anybody socially during the course of my treatments as I was just too unwell. My son who was seven years old at the time was exposed to witnessing my deterioration and he was clearly concerned about me, his mother was unsure if it was appropriate for him to see me in my condition, however I was able to convince her that I would protect him by presenting a good show and trying to conceal the experience. I am not sure this worked as I was no longer able to take him to the park or play with him as I did not have the energy; we used to be out all the time and now we were spending all our time indoors, with me sleeping on the sofa feeling unable to engage with him in any meaningful way.

Section 6: Treatment/Care/Support

16. Six months after completion of treatment my blood test results showed that I had not cleared the virus. I was devastated by this news, I was also told that there was nothing else that could be done for me and that I should try to adopt a positive attitude.

17. I was not offered any counselling or psychological support and it felt that I was being ejected by the NHS as the treatment had not worked. I experienced feeling very low and distressed, I was only 50 years old and I had been given a death sentence; not knowing how much time I had left and assured there was nothing that could be done for me, I was devastated by this news. I tried to minimise the impact on my family and friends by putting on a brave face but underneath I was very scared indeed.

18. I discussed this with my GP who felt so aggrieved by this outcome that she complained to the hospital. She wanted to fight the injustice and advocate for those who were not able to fight the NHS themselves. Once the compliant was made the hospital got in touch with me; they asked if I wanted to see the consultant. I declined and indicated that I was under the care of Professor Foster (see below) and what they were offering was too little too late.

19. Between 2005 and 2008 my symptoms continued to deteriorate. In June of 2008 I needed a procedure on my neck which required an injection of steroids into my spine. The Digestive Diseases Unit was contacted at the Royal Sussex County Hospital to check if the steroids could be tolerated by my liver; the consultant who contacted the hospital was assured that it would be fine, however, three days after the treatment I could not get out of bed and I continued to experience extreme fatigue for three weeks. I was sure my liver had struggled to cope with the steroids and I insisted on a blood test to see what was happening to my liver, sure enough my ALT level was 980, and my fibroscan score was 28 KPa. The NHS had told me that they could not help me with any further treatment for my infection and now they had made my condition worse by poor communication, procedures and protocols. I felt very angry with the NHS for their incompetence as I was now very unwell indeed.

20. In around 2009 I had a chance conversation with my friend GRO-A who reminded me that he had written a book about Hepatitis C treatment with Professor Graham Foster. GRO-A suggested that I see Professor Foster in London as a private patient as there was little chance of seeing him on the NHS as I was living in Brighton. My mother kindly agreed to pay for the consultation and I want to say that my experience with Professor Foster was the complete opposite from my experiences with the NHS in Brighton; he was the first person who gave me hope and told me that there were still options for me to consider.

21. Professor Foster was alarmed at my readings particularly after I had the small operation on my neck, when I was given the steroid injections. He had been monitoring me quite closely for a couple of weeks and he believed that the steroids accelerated the collapse of my liver and he did not like it. At the time, I was in serious trouble. After seeing the results from a second liver biopsy he decided to retreat me with interferon and ribavirin therapy. The treatment began within one week. This time however I was treated for 48 weeks at the maximum dose possible; during this round of treatment I experienced the same side effects as before but much more intensely. This second round of treatment was much more brutal because of the high dosage of interferon and ribavirin and I remember thinking at

week four how will I ever cope with another forty-four weeks of this? One of the worse side effects was the anaemia, my lowest reading was 8.5, this low level made it hard to breathe as I just didn't have enough red blood cells left to carry the oxygen that I needed to keep my body functioning. I remember going up to London on the train for my bi-weekly blood tests and being so unwell that I collapsed on the floor of the toilet on the train.

22. I am pleased to say that on completion of treatment I have been able to maintain a sustained virologicol response; however, my liver now shows signs of advanced cirrhosis and Professor Foster disclosed to me that he had in fact been very worried about me, and that I was only a few months away from going onto his transplant list for a new liver.

23. I am unsure as to why Professor Foster was not consulted over the steroid injections.

24. I don't know what would have happened to me had I not met GRO-A and found my way to Professor Foster. I expect I would have declined and found myself needing a transplant. I was given a death sentence and left to free-fall by the Royal Sussex County Hospital and I feel for all those who did not find their way to the expertise and treatment that I eventually received from Professor Foster.

25. My symptoms have improved however I still experience fatigue, low mood and short term memory issues. I have not been able to return to full-time work and I currently only feel able to work a three day week.

26. I have missed out on spending quality time with my son as I have not been well enough to attend his school functions and carry out the supportive duties that are expected of a parent, like watching him play sports or attend open evenings to speak with his teachers. I feel relieved that I am still alive to support him in any way I can, however I still feel a great sadness that he had to witness the brutal nature of the treatment and rapid deterioration that I went through during treatment; he should not have had to experience this, I know this was distressing for him.

27. I was given no psychological or emotional support during the whole of this period and it is only by the generosity of one or two friends that offered practical support; like doing my grocery shopping when I was too unwell or by just calling me once a week to say hello, that meant so much to me during the darkest days. I had no help with my son during this period; he spent most of his time with his mother as we have been separated since he was five years old. I do try and make up for the lost quality time, but I can never replace the time that we lost during his childhood and this leaves me feeling very sad.

Section 7: Financial Assistance

28. When I was first diagnosed a psychiatric nurse friend whom I met up with one evening for his birthday celebrations told me in passing that he knew of an organisation called the Skipton Fund that was able to offer some financial support to those individuals that were given infected blood supplies. If he had not told me this I expect I would not have found out. I subsequently applied to the Skipton Fund and I received a lump sum of £20,000 in November 2005. The application process was helped by the fact that I had supporting evidence from my doctor; he was sent a letter by the consultant surgeon who decided to transfuse me following the cholecystectomy procedure. If I did not have this letter I believe the process would have been very difficult indeed. This doctor has since passed away and when I sought my records I was told that they were just about to be destroyed.

29. When my liver deteriorated further and I was showing signs of advanced cirrhosis I applied for the Skipton Fund second stage payment and I was awarded £50,000 in 2012. I now also receive an annual payment of £18,000 that is now managed by EIBSS. I recently applied for a top up payment as I was experiencing financial hardship and EIBSS awarded a payment of £1,200 in August of 2018.

Section 8: Other issues

30. Being transfused with three units of blood on the 8th July 1985 changed my life

forever. It is impossible to say how my life would have developed had I not been carrying the infection for over thirty years. I am certain that I would have enjoyed a fuller hands-on relationship with my son, and that I may have been able to meet someone else and start another family, however this was denied to me because of the constant fatigue, brain fog and low mood that accompanied the infection. I feel very sad and frustrated that I have suffered in this way and that those close to me have also experienced suffering that could have been avoided.

31. I have felt that I have not been helped along my journey; information that could have been provided to me, to make coping with this serious illness has not been provided to me. I have found out things by accident.

32. I am now at increased risk of liver cancer because of the liver cirrhosis, and I continue to experience fatigue and short-term memory problems. I attend six monthly surveillance consultations and investigations with Professor Foster at the Royal London Hospital. I would like to thank Professor Foster and his team for their care, kindness and professionalism that they continue to show me, unfortunately this was not my experience at the Royal Sussex County Hospital.

33. I hope that the Inquiry will discover the whole truth as to how this tragedy happened and why it has taken so long to obtain justice. Many individuals have died while waiting for this Inquiry and the families of those that have died deserve to know what went wrong. It is my hope that the Inquiry will move quickly, and show some courage in saying what needs to be said so that lessons can be learned, and others will not suffer in the future.

Statement of Truth

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

GRO-C

Signed:

Date: 27th November 2018