

Witness Name: Dorothy Mary Wright

Statement No: WITN0789001

Exhibits: WITN0789002-04

Dated: 12.07.19

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF DOROTHY MARY WRIGHT

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 4 March 2019

I, Dorothy Mary Wright, will say as follows: -

Section 1. Introduction

1. My name is Dorothy Mary Wright. My date of birth is [GRO-C] 1950 and my full address is [GRO-C], East Yorkshire, [GRO-C]. I am married to Tony Wright and have one daughter, Debbie who lives in Spain. I intend to speak about my Hepatitis B. 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 on our lives together.

Section 2. How Infected

2. I gave birth to my daughter Debbie in [GRO-C] 1976 at Worksop Hospital, Nottinghamshire and that was when the problems began. I experienced heavy bleeding after giving birth and I had to have two Dilation and Curettage (D&C) procedures and blood transfusions. I bled again a few weeks later on [GRO-C] 1977 I had to have an

emergency hysterectomy. The bleeding was caused by chorea carcinoma. I was told that this was rare. I was referred to Weston Park Hospital in Sheffield, where I had a course of chemotherapy, radiotherapy and more blood transfusions. I then had more courses of chemotherapy and in late 1976 I was operated on to remove a tumour in my abdomen and on 12 December 1976 I was given a blood transfusion of 2 pints of blood. I had further blood transfusions on 22 and 23 January 1977 at The Weston Park Hospital, Sheffield, Yorkshire. I had further blood transfusions in 1978. **WITN0789003**

3. In early 1978 I was transferred to Charring Cross Hospital to see a specialist in chorea carcinoma and to undergo more intense chemotherapy. I underwent intense chemotherapy over the course of the next three years. It was during this period, that Dr Newman came onto the ward and told me I had Hepatitis B and that I was infectious and should be put in a room on my own.
4. I had so many blood transfusions over the years that it is difficult to know when exactly I became infected, though I assume it was during my treatment at Charring Cross Hospital in late 1978 because I had not been told about it prior to my hospitalisation there.
5. After being put in a room on my own I asked to speak to someone. I wanted to know what the future would be like with Hepatitis B and how it would affect my body.
6. A nurse told me that the Hepatitis was transferred through blood but she said, "We don't know how it's happened" and that, "It hasn't come from us, we haven't given it to you". Dr Newman told me that the Hepatitis B "Isn't our fault". In hindsight, I should have asked how he knew that.
7. I was later told that they could give me medication to stop it getting worse, but that I would always carry the virus.

8. Initially I wasn't given any medication. I was just told that I will be a carrier all my life, even though I might not suffer any symptoms myself.
9. I had weekly tests at Kingston General Hospital for a few years. I was relieved to find after having been tested that I was no better or worse.
10. Then the tests were reduced to fortnightly and then monthly. My levels during that time remained steady, and in the mid-eighties I was told that I did not need to be monitored any longer. I still hadn't been given medication by this point.
11. I was first put on medication for the Hepatitis, which I was on for 6 years. I was prescribed Lamivudine immediately after my transplant in March 2000. This was to control the Hepatitis B. This was changed to Tenofovir about 6 years later as blood tests showed the original medication was causing damage to my kidneys.
12. I currently take Tenofovir every other day.
13. I was never given much information about the Hepatitis, just that, if I were to get any cuts at home, I should cover them up immediately.
14. In terms of accessing dental care, I assumed that I should inform my dentist of the Hepatitis, but I was never told that I should. My dentist's attitude didn't change. He advised that I would be entitled to free dental care at hospital. I received NHS dental care at hospital for about 4 years, then, I was advised I could use the normal dentist care. I now have a private dentist.

Section 3. Other Infections

15. I have been asked about other infections which may have arisen as a result of receiving infected blood, however I am not aware of any other infections.

16. It should be noted however that as a result of my cancer treatment I have suffered from problems with my kidneys due to the medication I was put on in 2000, which was later changed. My right kidney no longer works which I was told was due to radiotherapy damage however, my left kidney does not work to its full potential either and I suffer from painful recurrent water infections and kidney infections which has resulted in hospitalisation on a number of occasions, including having stents fitted and removed 3 times. The latest operation was in June 2019 to remove kidney and bladder stones.

Section 4. Consent

17. I would not have agreed to the blood transfusions had I known at the time that the blood was coming from America, and the conditions under which blood was donated there. I was not told about any risks with blood transfusions.

Section 5. Impact

18. After being told that I had contracted Hepatitis B, I was left in a side ward alone with no explanation as to what was happening to me. I felt scared. I cried my eyes out, I was upset from the core of my body. I sat in isolation, with these thoughts in my head, feeling unclean.

19. I was discharged for a week or so between treatments, and was later readmitted to the main ward. I was surprised. But after a night I was put back into the side ward alone, for the duration of the course of treatment which was incredibly confusing. Initially I was alone in that room for three weeks, and then sent back there again for a further two weeks. After that I was always admitted to the main ward. The staff

always wore gloves when attending to me and until this day I have a special label on my blood and urine tests which is understandable.

20. Physically, I was already very unwell, so I cannot differentiate how I felt after contracting Hepatitis B.
21. I was discharged from the Hepatitis B tests at Kingston General Hospital in the late 1980s as far as I remember. I was no longer a patient there, in or out, when I first started having bowel problems. In 1999, I visited Castle Hill Hospital to investigate some problems with my bowels, which arose as a consequence of the radiotherapy treatment I had received for the cancer. A consultant at the hospital, Dr Lee noticed red spots on my body, which he told me indicated liver problems. He referred me to Dr J Smithson (at the same hospital) who discovered that I had suffered chronic liver damage as a result of the Hepatitis B. I had previously always thought that liver damage was caused by drinking and was alcohol related. I have never been a big drinker, so this shocked me at first.
22. My stomach was so swollen that the doctors and I would joke that I looked like I was due to give birth. That year, 1999, was hell and my illness dominated my life that year, it was a very stressful time.
23. I had two liver biopsies at Hull Royal Hospital. They missed my liver at the first biopsy attempt because it had shrunk so much, which was incredibly painful.
24. During my in-patient stays at Hull Royal Infirmary for my liver related treatment, I used to be in the same ward as alcoholics and drug addicts. Some nights, I would wake up and men would be standing on their beds and urinating on the walls. We shared a cubicle with one other person of the same sex and the cubicle walls didn't reach the ceilings. I was terrified, it was stressful and upsetting and I felt degraded. I would ring my husband and my mum and dad. I needed

the comfort and support from them. I would be asked to be taken home but the staff were very good and always calmed every situation. Just at the time it was stressful, upsetting and I felt degraded. I didn't know at the time what was going to happen.

25. It was between September or October 1999 that I was told the biopsy and other test results showed my liver was chronically damaged and I would need a transplant. Shock, horror, devastation! I was informed I would be referred to St James hospital in Leeds and they would assess me and decide what would happen. The next couple of months were so bad as I didn't know what was going to happen, 1999 was the worst year ever. Nineteen years ago, it felt like the end of the world. I was devastated, I thought I would die. I went through all that pain, only to be told I needed a transplant. My world collapsed.

26. I was put on a waiting list for a liver transplant in January 2000.

27. At first I didn't think I could do it. I didn't think I could take someone's liver when they had died. The doctor asked me to imagine that he was preventing me from falling down a cliff by a pinch of my clothing, and that he only had to open his fingers and I would be gone. That was how close I was to death. It is unimaginable the thoughts that spin round your head when you are on the brink, so to speak. I have a wonderful family and wanted to live, but would I? I wondered if I would get a liver in time.

28. In March 2000, I received a liver transplant at St James Hospital. The transplant was life changing and a huge success. I only realised how unwell I had been as a result of the liver damage after recovering from the transplant. I lived with so much pain, it wasn't only the pain, it was the weakness, the exhaustion, the weariness, which I had lived with for so long that I did not appreciate how unwell I actually was. After the

transplant those symptoms started to subside and I worked at becoming fully fit again.

29. Psychologically, at the beginning, I had blocked out that someone would die in order to get the liver. You do lose a life to gain a life, which is so unnerving and unnatural in my mind. It was hard to come to terms with. To this day, it still upsets me to think that I celebrate life whilst my lovely donor's family must still grieve their loss.
30. As the years went on, I thanked God that I had done it. At the time, it knocks you for six. I wondered if I would be able to go home and live normally. I thought I would be six stone, a little weakling. You get over the trauma of it, the medical and physical, you have to get over it. I did not want to let down the people who had donated the liver. It took me about four months to build my confidence up again to go out and do things on my own.
31. I felt contagious and am always concerned about what people think of my status. I always tell people, "It wasn't my fault", because I always thought it was something drug addicts get from using dirty needles. I wanted to work, but I couldn't because I was always in and out of the hospital for cancer treatment. It was for this reason that my mum and dad helped bring up Debbie up until the age of five. I have a very close family. When I became ill with liver problems, I wished the world would stop so that I didn't miss anything. You lose that time in your life.
32. In the beginning I thought my troubles would be over with the new liver and in my naivety I hadn't realised that my new liver could become damaged due to the hepatitis virus. I still have to go for check-ups usually six monthly, sometimes yearly. I really do like going because I feel reassured that the tests are done and that they are keeping an eye on me!

33. Shortly after becoming infected with Hepatitis, I wanted to work in a school but I also wanted to feel safe and be able to work with children. I wanted to know more about Hepatitis B, because I had very little information about it, so I went to the Infectious Disease Unit at Castle Hill Hospital off my own back to learn more about the condition. The doctor there was very good, and recommended that my husband and child should get tested too.
34. Both my husband and my daughter when she was older had the injection for Hepatitis B and have developed immunity to it. Tony regularly donates blood, and this year will give his hundredth pint. But still, to this day, they ask him out loud, in front of other people if he lives with anyone with Hepatitis. He has a letter to confirm that he is not infected, which he showed them, but it is very upsetting.
35. Tacrolimus was the first immunosuppressant I was prescribed in March 2000 immediately after my transplant. This was changed to Mycophenolate sometime in the mid 2000s, by Dr Davis, because Tacrolimus had affected my kidney function. My right kidney no longer works. Although I was told my right damage was due to radio therapy damage, my left kidney does not work to its full potential either. I suffer from recurrent and painful water infections and kidney infections. I have been hospitalised with these on a few occasions, including having stents fitted and removed three times. The latest small operation was in June 2019 when I had stones removed.
36. My medical records show that I was informed of my Hepatitis B infection in March 1978. **WITN0789004**

Section 6. Treatment/Care/Support

37. In 1981/1982 my GP referred me to Hull Royal to get some of my moles removed so I went to Hull Royal for a day surgery. The surgeon

asked me to get on the bed before he administered local anaesthetic. I reminded him that I had Hepatitis B, despite it being on my notes. The surgeon stopped the operation and packed up. He said, "Do you know how dangerous this is for other people?". I told him that it wasn't my fault, that I had been infected through blood transfusion. His attitude completely changed when he discovered my status and I left crying. He refused to remove the moles.

38. I do not think that I have ever been offered counselling, but I have always taken the view that, "We're managing, thanks. Ask the lady in the next bed". I do think we cope well. Life is for living and I have been given so many chances at a healthier life. I am lucky that we are a strong family and can cope. There are other people not so fortunate as me, so they do need the help.

39. Every 6 months or so, I go to St James for a check-up. When I get a yearly appointment, I tend to get another knockback and another issue pops up. Six months works well for me, and I do not have any concern with the treatment I receive now.

40. When I have been admitted to hospital for treatment the staff always wore gloves when attending to me and to this day my blood and urine tests have a special label put on them, which is understandable.

41. I would like it to be known to the Inquiry, that the staff at all the hospitals I have ever been treated in, have been very good. They all do their best under the circumstances. I have attached my medical chronology for reference. **WITN0789002** I have requested medical notes from Weston Park Hospital in Sheffield and have asked Charring Cross hospital in London to look again from my medical notes.

Section 7. Financial Assistance

42. I was not offered any financial assistance for my hepatitis infection or my liver condition or transplant. There were probably people who were more in need of it than us. I always felt we could manage, travelling to Leeds for treatment was not too far for us. Our social worker offered us help with expenses but we chose not to take it, because we felt we were comfortable enough to afford it.

Section 8. Other Issues

43. For my 50th birthday I did some fundraising and asked for money to donate to St James' Hospital in Leeds.

44. Five or six years ago, I wrote to GRO-C our MP about my situation but I was told that they were focussing on haemophiliacs so I never pursued this further.

Statement of Truth

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

Signed _____

GRO-C: Dorothy Mary Wright

Dated _____

12.07.19