

Witness Name: B Dennis
Statement No: WITN1185001
Exhibits: WITN1185002-4
Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF BARRIE DENNIS

I, Barrie Dennis will say as follows:-

Section 1. Introduction

1. My name is Barrie Dennis. My date of birth is GRO-C 1949. I live at GRO-C with my wife Debbie.
2. This witness statement has been prepared without the benefit of access to my full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.
3. Where specific dates are not given this is because I cannot recall the exact dates due to the passage of time.

Section 2. How infected

4. I suffer from mild/moderate Haemophilia B (also known as Christmas Disease) which means that I have a Factor IX deficiency.

5. I needed many transfusions of blood platelets and sometime between the 1970s and 1986, I believe I was transfused with infected blood products. My treatment record from the UK National Haemophilia Database is exhibited at **"WITN1185002"**. This goes back to 1977 and shows that I was treated with Factor IX from BPL in Elstree on 7 occasions between 1977 and 1989. I was often treated with Factor IX for dental work.
6. I was only ever told that my Factor IX was £1,000 per shot and was made up of blood plasma from hundreds of people. I was not given any other information about the product or told of any potential risks of the treatment.
7. In the late 1980s, when I was under the care of the Royal Free Hospital in London, I was called in and told that I had Hepatitis B. I was put on medication. At that time my care was overseen by Professor Lee.
8. A few weeks later I went back in and was told the good news was that I was clear of Hepatitis C but the bad news was I had been infected with Hepatitis C. The virus had only just been identified and I remember asking whether Hepatitis C was the virus I had heard about on the news. I was told that it was. They asked me if I had any idea how I had contracted it. I said "I have no idea, probably something you did."
9. I then had to tell Debbie the news. At the time she was a nursing sister at St Mark's Hospital and she knew that she would need to be tested.
10. I was infected with Hepatitis C (Type 3) as a result of receiving contaminated blood products. I have never been told when I was infected. When I was told of my diagnosis I was not given any information (written or otherwise) regarding the disease or possible routes of transmission.
11. When repeated gum infections were affecting my new liver I was advised to have my teeth removed. This was done at Warwick Hospital. It has been a nightmare because of the fitting. My teeth keep falling out which is embarrassing. I try to make a joke out of it when it happens but it has affected my confidence. For example, I recently went to New York for

Debbie's 60th birthday and my teeth fell out in a hotdog at Madison Square Gardens in front of my son.

Section 3. Other Infections

12. My UKHDO records state that I was tested for HIV by the Royal Free in 1986, 1987 and 1991.

13. They also state that my vCJD risk was assessed on 24 September 2004. I was not told much about this potential disease I recall getting a letter about vCJD which said that I might be at risk. When I asked about this I was told that it could only be diagnosed by a brain biopsy which I couldn't have because of my haemophilia so it was a case of "watch and wait".

Section 4. Consent

14. When I attended at the Royal Free Hemophilia Centre for treatment or clinic reviews I always had blood tests but was never told what they were for.

15. After I was given my Hepatitis C diagnosis I recall being told that I would be tested every now and then. At first I was told that this was to see how the Hepatitis C was progressing. In the early 2000s I was then told that I was HIV negative and that the incubation period was 13 years so they thought I was now "in the clear".

16. There are references in my medical records to tests for HIV in 1986 and 1987 however, to the best of my recollection, I was not asked to consent to this testing.

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18. I do not know whether research has been carried out on any samples which may have been held by the Royal Free. However, they wrote to me in June 2007 to try to allay fears that research had taken place without consent. This letter is attached as **"WITN1185003"**. Although this letter states that no testing had been done for vCJD (as suggested at the time in the press) it does refer to an earlier research programme. I do not recall being asked whether samples could be stored for research purposes.

Section 5. Impact of the Infection

19. I have associated Hepatitis C Polyarthrititis which affects both my hands, feet and joints. This was diagnosed by Dr Dunn, a rheumatologist at Warwick Hospital.

20. This means that, at times, I cannot perform simple tasks and carry out the normal activities of daily living. The pain is horrible. I used to like to paint and would sew, however I can't do anything like that anymore. I am always asking for help with the smallest of tasks, such as opening things, putting socks on, doing me belt up etc. I find this very frustrating.. I am now taking hydroxychloroquine for it but this can affect your vision in the long term so I am on annual review for this medication.

21. I am also more prone to any form of cancer than the average person as a result of my infection.

22. I have chronic lung disease and bronchiectasis which means I have constant opportunistic lung infections requiring antibiotics when purulent. This affects me on a daily basis. I am now very rarely without a cough.

23. When I was diagnosed with Hepatitis C I felt it was a death sentence. I have been told twice in my life that I only have 2 years to live. I have suffered from depression and a feeling of lack of self-worth. I have found this very hard to deal with. I have not had any counselling and have relied on my family and close friends for support. I can only describe it as the feeling of dark clouds

descending – I couldn't imagine a future or think of anything happy. I know that this took its toll on Debbie as well because I was not easy to live with.

24. I was treated with Pegylated Interferon and Ribavirin in the late 2000's. This was unsuccessful. This gave me flu-like symptoms, dizziness and bad depression.
25. I was given the treatment again within a year and suffered the same side effects. Looking back I wonder whether I was given another go at treatment so quickly because they knew that I had been infected via contaminated blood products.
26. Warwick Hospital took over my care in the mid 2000s and in or about 2005 I was diagnosed with bowel cancer. Because of the complex nature of my case I was referred to the Royal Free for treatment.
27. I needed an anterior resection which was eventually carried out on 6 July 2005. However, the consultant, Professor Winslett, was extremely reluctant to operate due to potential contamination in surgery and the huge cost to the Trust. He said that he had 3 daughters and if he operated on me, even double gloved, if he got HIV or vCJD he would never be able to operate again. I walked out of the consultation I was so disgusted and felt that I had been left to die. I have 2 sons but they did not seem important to the professor.
28. I was made to feel like a burden and a leper. A copy of Professor Winslett's letter is attached as **"WITN1185004"**.
29. After the resection I was referred back to Warwick Hospital under Dr Harris and Dr Shearman. The cirrhosis of my liver was diagnosed in 2005 as a result of the investigations I had for my bowel.
30. Dr Shearman then found shadows on my liver and referred me to Dr Wilde at the Queen Elizabeth Hospital (QEH) in Birmingham because of the added complication of my haemophilia as well as the Hepatology/oncology dept

31. I underwent TACE at the QEH. This was through the groin and was very painful. The idea was to shrink the tumour a bit and then scan again in a few months to see what the position was.
32. When I was next scanned the cancer had come back aggressively and they found 6 tumours. I had a further round of TACE to shrink the tumours and was put on the list for a liver transplant.
33. I had a liver transplant in 2013 at the QEH from a live donor as part of a domino scheme. This meant that donor liver went to a young person (under the age of 25) suffering from Amyloidosis and the young person's liver was transplanted to me. The idea was that it would be 30 years before Amyloidosis would be likely to become an issue for me and I would undergo checks every 5 years.
34. I have in fact already undergone painful neurophysiology tests to ascertain whether I have contracted Amyloidosis from the donor liver.
35. The steroids I was put on after my transplant made me bloated and extremely depressed and emotional. I would cry at random adverts on the TV.
36. I have been on immunosuppressant medication since the transplant to protect against rejection of the new liver. This has left me more susceptible to other infections, particularly UTIs and kidney infections.
37. Whilst in hospital for the transplant I had acute renal failure requiring dialysis and emergency surgery for an internal bleed. This almost killed me, and at 4am they had to rush me back to theatre. I also contracted *C.Diff*.
38. I was in ITU for 4 weeks (including Christmas Day) and when I left the hospital I could barely walk. I had a wound bag and 2 sticks. Debbie had to call an ambulance shortly after I was discharged because I was so unwell and we were not coping. Because I was transported by ambulance the protocol is for the ambulance to go to the nearest hospital which was Warwick. Debbie and I both knew that I would need to go back to the QEH but the ambulance would not take us so I spent 4 ½ hours in A&E at Warwick Hospital on New Year's

Eve before being transferred to A&E at the QEH and waiting another 3 hours. It was horrendous.

39. The liver transplant has been a success so far but there have been complications which has had a huge impact on my life including the increasing certainty that I now have Amyloidosis.
40. Following my liver transplant I had an incisional hernia. The microsurgeon was unable to repair this as the risk is too high. This gives me terrible constipation; I have been admitted to hospital before regarding this. This is unsightly and there is a risk of contortion. I now suffer from body image issues particularly if we are away with the grandchildren and one the beach. I try to make a joke out of it but it does affect me. The only way to resolve this would be to spend 8 hours in surgery with a high risk of complications.
41. My new liver has also been infected with Hepatitis C which makes me feel like I am back where I started.
42. In or about August 2018 I noticed a lump in my shoulder. I went to the GP who cut it out and gave me 7 stitches. I then got a call to say that it was squamous cell skin cancer and that because I am immunosuppressed I will be prone to skin cancer. I have had several other tumours identified and removed since then.
43. In or about 2017 I completed a course of Epclusa treatment for my Hepatitis C. I was told that the cost on the NHS was £54,000 but that I could get it direct from the drug company in India for £4,000 and the NHS would then administer it and monitor me. The NHS contract for the drug was with America which was why they could not source it from India. Needless to say I did not have a spare £4,000 to purchase the drug so I had to wait for funding to be granted. My treating doctors at Warwick Hospital really pushed for me to be given the treatment.
44. My Hepatitis C is currently under 12 which means it is a low level and although I haven't cleared the virus.

45. I times I have been made aware that there have been disputes between the QEH, Warwick Hospital and my GP over who funds my medication. These sorts of things make me feel very uncomfortable and like I am a burden.
46. All of the above has left me without any dignity of purpose in life. My independence is limited.
47. I find it hard to get holiday insurance which means I cannot go to Italy to see my family. I do not have life insurance as no company will insure me. Everything we have is in Debbie's name. This has affected not just me but my whole family. I managed to get insurance to travel to New York for Debbie's birthday but this cost £500 for four days and only provided cover to fly me back to the UK if I was taken ill.
48. Debbie is an Ophthalmic Nurse specialist who works for the NHS. She has worked over and above her full time hours and was in a debt management programme to keep our heads above water financially. I didn't realise that she was using one credit card to pay off another and that we were in financial difficulty.
49. When I worked I worked in graphic art and spent time working abroad. Since my Hepatitis C diagnosis I have not really been able to work. I tried to do the odd bit of building surveying work for a friend's company but it was too difficult with my illness and all the medical appointments I have to attend. Managing my illness is like a full time job given the number of different medical appointments I have to attend.
50. When I wasn't able to work I approached the DWP for assistance but was told that I was not eligible for support because my wife worked but that if she reduced her hours to 16 ½ hours a week I would then receive benefits.
51. My infection also affected Debbie's work life because, following my diagnosis, she was unable to work in certain areas of the hospital until she had been tested for Hepatitis C and given the all clear.

52. My illness has also had an impact on family life. It means that I could not be the father I wanted to when the children were growing up. As a result of required medical treatment directly related to my Hepatitis C infection I missed my son's graduation from university which, to this day, remains a great sadness to me. It has also affected my ability to be a grandfather. My daughter in law sometimes doesn't want me to spend time with the grandchildren because of my respiratory infections.

53. I have not directly experienced the stigma associated with my condition because I have only confided in close friends and family.

54. I would have liked to give my body to medical science but as a result of my Hepatitis C and its consequences I have effectively been told that medical science does not want me.

55. I have been in touch with my local MP, Nadim Zahawi over the years who has been extremely supportive to me and my family. He has also mentioned me a few times in Parliament as we have campaigned for answers. Prior to speaking to him Debbie had written to a number of firms of solicitors to see whether there was any action we could take in relation to contaminated blood but we didn't get anywhere.

Section 6. Treatment/Care/Support

56. I was offered counselling before my liver transplant. This is a big part of the pre operative work up. However, I was not offered counselling when I was diagnosed with or when I was undergoing treatment for the Hepatitis C.

57. I don't feel like I have had to fight for my treatment personally but my doctors have had to fight for me.

58. I believe the QEH and Warwick Hospital have done really well in their joined up care in looking after me.

Section 7. Financial Assistance

59. I applied to the Skipton Fund in October 2004. My form was completed by Professor Christine Lee. This was for the Stage 1 payment of £20,000.
60. I made a further application in October 2005 for the Stage 2 payment.
61. I found out about the Caxton Fund through our MP Nadim Zahawli.
62. I initially applied to Caxton for help with our travel expenses to and from Warwick Hospital. They also provided funds when our roof fell in, and provided a contribution to a more accessible bathroom for me.
63. However, after they contributed £2,000 towards the bathroom things because difficult. We sent in our next set of travel expenses and were told that nothing else would be paid until they saw the bills we had paid for our half of the bathroom work.
64. It felt like we were permanently being questioned and that we were never believed. We were made to feel like we were beggars.
65. I now receive £1,500 per month from EIBSS which has changed my life. I don't think I would have survived much longer without this. I also receive PIP and the State Pension

Section 8. Other Issues

66. My UKHDO records are incomplete. These were printed on 30 October 2018 and state that I have not had a liver transplant when I underwent the same in 2013. They also state that I have not had Hepatocellular carcinoma.
67. Although I am grateful for the help I have received I feel I have been given a life sentence on death row without having committed a crime. I feel so let down by the never ending battle to receive some form of final settlement to help me and others like me financially. If this were achieved I feel it would

help us feel that we had some worth and therefore would help emotionally as well as financially/practically.

68. I want to be able to give my family financial security not just for a year after I die but a financial amount that will help compensate for the life that we did not have; the life that was taken away firstly by the receipt of contaminated blood products and then by the refusal to investigate and fully compensate victims of the scandal.

Anonymity, Redaction and Disclosure

69. I do not want to be anonymous.

70. I would give oral evidence at the Inquiry if required.

Statement of Truth

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

Signed. GRO-C

Dated..... 26.11.18

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

- 24.08.2008 Letter from Warwick Hospital. Confirmed recent blood tests showed he was responding well to treatment. The hepatitis C virus appears to be clearing very well. This is really good news.
- 18.02.2009 Letter from Royal Free re vCJD. There have been recent reports in the media about a person with haemophilia who was found to have the agent that causes vCJD in his spleen post mortem. We are enclosing information from the UKHCDO and the Health Protection Agency to give you as much information as is currently known.
- 11.09.2009 Letter from Royal Free to University Hospital Birmingham. I would be grateful if you could take over care of Mr Dennis who is currently under the care of the Haemophilia Centre at the Royal Free Hospital for mild haemophilia B....He has also had an anterior resection for rectal cancer in July 2005, and I understand at that time, the margins were clear. He was last reviewed in 2008 in the Joint Haemophilia/Hepatology Clinic, and at that time a discussion was about treatment. I understand subsequently in conversation with him by one of our nurses that he has received treatment locally and has not responded. At the time of surgery, a cirrhotic liver was also noted. He is on the variant CJD at Risk Register for Public Health purposes.
- 26.11.2009 Letter from Warwick Hospital. I am pleased to report that your liver scan is unchanged. Your liver blood tests still show a degree of inflammation consistent with your hepatitis, but there were no other significant changes.

26.07.2011	Letter from Warwick Hospital. Following our last conversation at the clinic I have discussed your care with Dr Mutimer who works at the Queen Elizabeth Hospital in Birmingham. He has pointed out that the new drugs that are due to be licensed at some point in the near future would not be particularly effective against your virus, but he would be happy to meet you to discuss forthcoming clinical trials that may be available through his department.
25.04.2012	CT Colonoscopy Virtual. Liver normal.
07.04.2013	Letter from Warwick Hospital. I am pleased to report that your recent blood tests are all satisfactory. Your ultrasound has shown a small patch in the liver that the x-ray doctors think would be better characterised with an additional scan.
07.06.2013	Letter from QE Hospital Birmingham to Warwick Hospital. We reviewed the images in our MDT. There are a total of probably five lesions within his liver, only the larger areas are diagnostic of hepatocellular cancer. There is either one large lesion measuring 32 mm or two lesions measuring 18 and 14 mm respectively (depending on your perspective) they are touching each other in segment eight of the liver and there are possibly smaller satellites around this lesion. In addition, there is a 26 mm lesion in segment seven of the liver. These lesions are the ones that are proven HCC, the other small areas are possible. We felt in view of his age and the potential aggressive nature of the disease that we should consider transarterial chemoembolization and evaluate (TACE) the response to this treatment before possibly considering other more definitive therapy.
01.11.2013	Letter from QE Hospital Birmingham. Oncology discharge letter. Admitted 31 October, discharged 2 November (planned).

Admitted for anti cancer treatment. Elective admission for TACE procedure.

- 07.11.2013 Letter from QE Hospital Birmingham. Please find enclosed a letter to your GP for hepatitis B vaccination.....You are on the transplant list but suspended until 22 November following your TACE.
- 01.01.2014 Admitted to QE Hospital Birmingham with severe diarrhoea until 5 Jan.
- 10.01.2014 Letter from QE Hospital Birmingham. I was pleased to review Mr Dennis who came to our follow up clinic along with his wife 29 days after his liver transplantation for hepatitis C that was complicated by HCC. This pleasant gentleman received a full sized graft from liver donor on 10 December 2013. Following surgery he underwent relapartomy for bleeding on the 5th post transplant day. Following that he had a good recovery. His renal function improved and the patient was discharged home on the 25th post transplant day. I was pleased to see he continues a good recovery. He is getting more active. He is completely off painkillers.
- 12.02.2014 Letter from QE Hospital Birmingham. I was pleased to review Mr Dennis who came to our follow up clinic two months after his liver transplantation for hepatitis C that was complicated by HCC. This pleasant gentleman received full sized graft from a domino liver donor. I was pleased to see the patient continues to do well. His blood results are normal. The patient bowel habits are normalised and he has stopped his antibiotic treatment for C diff recently.
- 13.08.2014 Letter from QE Hospital Birmingham. I reviewed him in Hepatology clinic.....This gentleman had a liver transplant in

December 2013 and was found to have raised ALT and AST levels a couple of months ago. His ultrasound abdomen performed a couple of days ago at his local hospital revealed a patent hepatic artery, portal vein and inferior vena cava. CMV DNA quantification was less than 200 copies/mL (July 2014). HCV RNA quantification is 7,74,714 IU/mL (15 July 2014). His lab reports were received by Prof Mutimer who felt that it was most likely he has HCV related liver damage, and rejection at this stage post transplant is most unlikely.....

- 24.11.2014 Letter from Warwick Hospital. This mans sputum culture has come back showing Moraxella catarrhalis. Reviewing his CT scan he does have definite bronchiectasis and this may explain the Staph aureus and the Moraxella that we have even more recently isolated. As he has an going problem with a cough it would be worthwhile trying 2 weeks of Doxycycline 200mgs daily...
- 13.01.2016 Admitted to Warwick Hospital. Patient admitted with diarrhoea, vomiting and muscle cramps...He feels symptoms and smell of the diarrhoea matched his previous c diff infection. He was found to have an acute kidney injury on his blood results. Stool sample showed 1 positive c diff culture from 3..... Recovered quickly and renal function returned to baseline 2 days later.
- 02.12.2016 Letter from Warwick Hospital. He is in good spirits and his respiratory status has been stable since a course of antibiotics and steroids in June of this year.