

Witness Name: Fiona Ruth BOYCE

Statement No.: WITN0155001

Exhibits: **WITN0155002/5**

Dated: 09/02/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF FIONA RUTH BOYCE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 20th November 2018.

I, Fiona Ruth Boyce, will say as follows: -

Section 1. Introduction

1. My name is name is Fiona Ruth Boyce. My date of birth and address are known to the Inquiry. I live with my husband and two children. I have lived at my current address for 21 years and we run our own business. I was born in Harlow and have always lived in the Hertfordshire area.
2. In this statement I intend to describe my infection with the virus Hepatitis C (hereinafter referred to as 'HCV') from contaminated blood given to me during a blood transfusion when I was newly born. I will go on to describe how this affected my family and myself. I will also describe the treatment which I received and the impact it had on our lives.

Section 2. How Infected

3. I was infected by one or both of the exchange blood transfusions after I was born. In 1968 my mum fell pregnant with me, her third child. My mum was admitted to Princess Alexander Hospital, Harlow, Essex.

GRO-C

GRO-C

My mum has told me that her antibodies viewed me 'as an infection' attacking her body and her antibodies were fighting to 'kill' her baby. After my birth the condition was diagnosed as 'haemolytic disease of the new born'. My mum informs me that following my birth I was ill and was taken away to a special unit for care.

4. I received an exchange blood transfusion on the day I was born. My mum believes she was GRO-C after the birth and was herself being treated so was not with it. She does not remember anything of my treatment. My father, who was also there and would have known, is no longer with us to clarify. My serum B rose to 22.5 mg per 100ml so a second exchange transfusion was carried out the day after, this is confirmed by my birth records. After my birth I was kept in hospital for 3 weeks. I was prescribed and given one week of ampiclox following the exchange transfusions. During the second and third week my records showed that I was slow at gaining weight but no evidence of any infection was found. We were discharged home on the 8th July 1969.

5. My mum cannot remember what she was told or by whom in the days after my birth. My mother is adamant that neither she, nor my father, were informed of any exposure to a risk from treatment being administered to me following my birth. I was infected with HCV as a result of one or both of the blood transfusions given to me following my birth.

6. There were two separate instances when I was notified that I had been infected with HCV.
7. I started to donate blood as soon as I was old enough to do so. I had always been conscious of the fact that the blood transfusions, I received at birth, had effectively saved my life.
8. After leaving school I joined Barclays Bank in December 1987. They had a facility for their staff to donate blood. We used to go along to a church hall in the city near Fenchurch Street. I donated blood there a total of 5 times. My blood donor card shows that I donated blood on 10th October 1988, 4th April 1989, 12th October 1989, 7th May 1991 and on the 10th May 1993.
9. I received a letter from Dr Angela Gorman, Consultant Haematologist from the National Blood Transfusion Service dated 4th August 1993. The letter was sent to me at home. The letter thanked me for being a blood donor and for donating blood. I was advised not to be alarmed, however the letter informed me that their tests had indicated the presence of antibodies in my blood, which confirmed that at some point in my life I had been infected with the HCV. This was the first notification I ever had that I had been infected with HCV during my lifetime. I have given a copy of this letter to the Inquiry, which I refer to as **Exhibit WITN0155002**.
10. The letter from Dr Gorman stressed that HCV had no association with the HIV virus and there was no suggestion that I was ill. The letter advised that the symptoms could be very mild and not to worry unduly. I was advised that the HCV was not infectious to my family or friends and it could only occasionally be passed on via a blood transfusion.
11. In addition Dr Gorman requested that I refrain from donating blood again for the reasons given and not to carry my donor card. It was recommended that I contact my GP for further advice. Dr Gorman

sought my permission for a copy of my test results to be sent to my GP who could then make any appropriate referrals to further specialists, if I so wished. I was also invited to contact her by telephone if I had any further questions.

12. I telephoned Dr Angela Gorman the same day, upon receipt of the letter whilst I was at work. We discussed the potential ways I could have been infected. I confirmed I had only pierced my ears once and that I had one partner and no history of drug use. By process of elimination we determined that I had contracted HCV via one or both of my blood transfusions at birth.
13. My immediate concern was as to whether I had passed the infection to other people namely my husband and to others through my donated blood. I understood from my conversation with Dr Gorman that the HCV infection was no longer present but that I did still have antibodies in my blood. I was also advised that this medical history would have no bearing on my ability to have children. As such my concerns were allayed and I felt reassured that I had nothing to worry about.
14. Dr Gorman did not go into the fact that I had donated and potentially passed on the virus to others. I gave Dr Gorman written permission for the National Blood Transfusion Service to contact my GP, however I cannot remember if I did see my GP and if I did do so I did not come away with any concerns because I would have remembered this. From my GP notes, there is a letter from Dr Gorman to my GP dated 11 August 1993, I refer to as **Exhibit, WITN0155004**. With it she attaches a document entitled '*Recommendations for Doctors caring for blood donors found to have a positive HCV antibody test*'. This clearly stated that I should be offered a referral to a specialist, - either Professor Dusheiko at the Royal Free, or Dr Murray-Lyon at Charing Cross Hospital. This did not happen until 1996.

15. I believed at that time, that I was, given adequate information by Dr Gorman about HCV, to help me understand and manage the same, however I also believe that this information should have been communicated to me earlier. In my opinion somebody would or should have had a record of the blood transfusion at my birth and should have been aware of any knowledge of any risks of a blood transfusion and alerted my parents of those risks.
16. I became pregnant with my first child in 1994. In the early stages of my pregnancy I was suffering from symptoms of excessive skin itchiness, which was causing me extreme skin irritation. I also suffered symptoms of jaundice from July 1994. I brought this to the attention of my Obstetrician, Mr Morcos at Chase Farm Hospital who conducted an antenatal test (ELISA). The test revealed that I was HepC antigen as previously advised by Dr Angela Gorman at the NBTS.
17. Mr Morcos referred me to Dr S Vijeratnam, Consultant Community Paediatrician at Highlands Hospital, London N21. Mr Morcos informed Mr Vijeratnam of the result of the ante natal screening and also advised him that I had been aware of this diagnosis for two years prior. I confirm that I knew that I had at one time carried HCV, however I was unaware that I was still infected at this time. In my mind this was the second time I was notified that I had been infected with HCV at some time in my lifetime.
18. Mr Vijeratnam wrote to my GP, Dr Roberts at Stockwell Lodge on the 28th September 1994. I have given a copy of this letter to the Inquiry which I refer to as **Exhibit WITN0155003**. Mr Vijeratnam stated that I had probably become infected with HCV as a new born when I was given a blood transfusion for rhesus incompatibility. He discussed my case with Mr Mummery, Consultant Microbiologist at Chase Farm and with Dr Julia Heptonstall, Head of Hepatology for the Communicable Disease Centre and he recommended that I be monitored throughout my pregnancy for HCV at the Liver Unit. Mr Vijeratnam recommended

that I be referred to Professor Neil Macintyre, Liver Unit at the Royal Free Hospital.

19. I attended Chase Farm Hospital at the end of September 1994. Mr Vijaratnam advised me that I should not go back to work. I was informed that I had a diagnosis of cholestasis, a condition where the liver is not functioning properly and causes jaundice.
20. I attended with Professor Macintyre at the Royal Free Hospital on the 27th October 1994. Professor Macintyre felt that there were few treatment options he could offer to me whilst I was pregnant and he suggested I return to him a few months later.
21. I returned to see Professor Macintyre on the 1st December 1994. He recommended that I attend for a liver biopsy after my baby was born. This was booked in for 8th February 1995 however I decided not to proceed with this appointment because my baby daughter was not well at that time [REDACTED] GRO-C [REDACTED] I received a letter from the Royal Free Hospital in February 1995 confirming my instruction to delay the biopsy and advising that I would continue to have regular blood tests in the interim period. Based on the tone of the letter I did not feel it was a serious issue and I felt I could concentrate all my energies on my newly born daughter. I have always wondered if [REDACTED] GRO-C [REDACTED] I was re-booked in for a subsequent appointment on the 13th March 1996 for a liver biopsy.
22. I attended for a liver biopsy on the 13th March 1996, the biopsy results *eventually* revealed evidence of cirrhosis on my liver. In my notes from The Royal Free, there is a copy of a letter I sent on 23rd May 1996, I refer to as **Exhibit WITN0155005**, asking why I had not received an appointment following my liver biopsy. I had already needed to phone a registrar to get the results and was now, *6 weeks after the biopsy and 3 weeks after the phone call*, chasing them again, in order to get any

answers. The Royal Free wrote to my GP on 15th May and gave him my results, but I wasn't seen until 18th June 1996. It was after this appointment that Professor McIntyre referred me to Professor Dusheiko

23. In terms of my being informed of my infection with HCV, I believed I had received adequate information about the infection. I was advised to have my baby tested for HCV at Stockwell Lodge. GRO-C
- GRO-C Despite this and in hindsight I feel that as before, the seriousness of the infection was never communicated to me. I did not relate any symptoms of tiredness or anything else between the two notifications of HCV as attributable to the virus. Further, I do not believe I contracted any other medical conditions as a result of my blood transfusions.
24. As regards consent I always just agreed to blood tests. I never had concerns as to what I was being tested for during my pregnancy. I just assumed it was all straightforward testing. I just believed that they were medical experts and they knew what they were doing.

Section 3 : Other Infections

25. To the best of my knowledge I am only aware of being infected with the HCV as a result of the two blood transfusions that took , following my birth.

Section 5. Impact

26. When I became aware that I was infected with HCV this caused me a great deal of mental upset, worry and stress. I feared that I might have infected my family. To this day I still worry about whether I have infected other people who have received my blood through my donations. The treatment for the condition was tough and I was hard to

live with. I had to delay our family planning for a second child and I was faced with an uncertain future of cirrhosis of the liver or liver cancer.

27. I recall that I suffered from anxiety at the age of 11 and it surfaced in 1987 when I started my job. It is difficult for me to establish whether the onset or vulnerability to anxiety was related to the underlying HCV in my body. I did however develop a coping mechanism.
28. I also suffered physical effects of being infected with HCV. I started treatment for HCV treatment in July 1996.
29. I believe the physical effects of HCV only really became obvious during my pregnancy as they showed up by way of itchininess and jaundice. It is difficult for me to attribute any other symptoms due to HCV. I would not say I was unduly tired between the years 1969-94.
30. As I was now aware of my liver condition, I was told not to drink too much. I have had my liver tested many times and it is in good condition now. I attended for a biopsy, scans and ultrasounds and I underwent the hepatitis treatment.
31. On the 13th March 1996 I was admitted into hospital for a liver biopsy. I had to stay in overnight and leave my young daughter so this was difficult for me. The procedure itself was also very painful. I was taken into a room and I was injected through the right side with what felt like a huge instrument. Thereafter I was checked on all night so my sleep was interrupted all night. My right shoulder was in agony and I was prescribed only one paracetamol, which provided relief and which proved to me how strong paracetamol is. I had to use a bed pan as I was not allowed out of bed. I felt an overwhelming tiredness.
32. I also underwent an endoscopy on the 12th May 1997 to establish if I had oesophageal varices, a condition caused by HCV. The condition causes swollen veins in the oesophagus and the stomach which can

rupture. A common cause of this condition is cirrhosis of the liver. A camera was lowered down my throat as part of the procedure and this was very unpleasant. The test results were clear however I was warned that there was a risk that liver cancer could occur in my lifetime.

33. I was admitted for Alpha Inteferon treatment on the 31st July 1996. I went into the ward at the Royal Free Hospital and was seen by one of Professor Dusheiko's research sisters at 10am. I had my first treatment there and remained for a couple of hours to see if there was any adverse reaction. My husband and I were shown how to self inject and administer the treatment. I was then given about three weeks worth of treatment to go away with and come back.
34. The Interferon treatment consisted of taking three injections (3 million units) per week. I did not feel able to self inject and I relied on Mark to help me. Mark administered the injections three times a week, on a Monday, Wednesday and on a Friday. I carried out this treatment plan for three months.
35. I suffered definite side effects during the treatment period. I recall feeling generally awful. Even though I wasn't working at the time and I was at home with my daughter I felt tired and wiped out. I was also aware that I behaved irrationally and horrible between Friday and Monday as there was a two day gap then between the treatments. I was shorter and sharper tempered than otherwise.
36. I continued to have regular blood tests. After three months the Alpha Interferon treatment was stopped because despite an initial drop in the virus levels it had risen back to its former level.
37. I attended hospital for a series of mental tests following the Alpha Interferon treatment. I underwent the SPEM/EEG test which measures brainwaves. The purpose of undertaking this test was to ascertain

whether there was any evidence that the brain had become slightly slow which could be caused by liver cirrhosis. I underwent this test on the 17th March 1997 and the results were normal. I also made note at the time that I had psychometric testing and again the results were all fine.

38. In April 1997 I underwent an ultrasound of the liver. I was told that the Alpha interferon treatment plan had failed and I was offered an alternative course of treatment. Professor Dusheiko's team advised me of a new Combination therapy Inteferon and Ribavirin, which they were happy to trial with me. I was informed that I was one of the first group of people to trial this particular drug. I agreed to the treatment.
39. The treatment plan was a combined treatment consisting of my taking six tablets of ribavirin a day and three injections of interferon per week. I followed this course of treatment for six months and I completed the treatment on the 6th October 1997.
40. I attended for liver function blood tests and the result was that my liver function was now within acceptable levels and the HCV was non-detectable following this course of treatment.
41. I was told I should wait another six months before trying for another child. This would take me up to March 1998.
42. All in all, the treatment period for HCV was between 1996 and 1998. Because of this we did not have the opportunity of having our second child. But for this period of illness, I would have had a smaller gap between my two children.
43. At the end of my treatment I was tested regularly and was tested on the following dates: April 1988, August 1998, 21st October 1999, 17th August 2000, 16th August 2001, 22nd August 2002, 9th September 2004, 13th September 2007 and the 24th March 2011.

44. I was discharged by Dr S Tanwar, a member of Professor's Discheko's team on the March 24th 2011 at the Royal Free Sheila Sherlock Liver Centre. The conclusion of the tests noted that I had been symptom free for a while. The tests indicated significant regression of fibrosis in my liver and I was informed that no clinical need or hepatoma clinical surveillance was required thereafter.
45. In terms of the treatment plan following the diagnosis of HCV I do not feel that there was any particular delay in receiving treatment. Everything appeared to move smoothly along and I always felt quite lucky with my referrals. Any delay in treatment was of my choice.
46. I was not aware of any treatment that was available at that time, but was not made accessible to me.
47. On the 1st June 2015 I found a lump in my right armpit and saw my GP. She referred me to the local hospital. ON the 15th June 2015 I saw a Consultant, Mr Agarwal at QEII Hospital. ON the 17th July 2015 I had a mammogram and an ultrasound, which found nothing and a biopsy of the armpit lump. On the 10th August 2015 I saw Mr Agarwal. He confirmed that the lump was secondary cancer and I was booked for a CT of neck, thorax, abdo and pelvis with contrast, and an MRI of the breasts. This was to find the primary cancer. I was not aware that they knew it was breast cancer. Because of my HCV diagnosis I thought it was liver cancer and that was why they were checking everywhere.
48. My son had started his GCSE exams on the same day I had discovered the lump and that summer was the first time my son started GRO-C My husband and myself kept all my tests private from everyone until the diagnosis of breast cancer was confirmed on the 10th August 2015. Those two months were the scariest time of my life.

49. I attended for breast surgery on the 8th October 2015 and I was assured that the cancer had been removed. At the end of November I started a six week course of chemotherapy and all my veins collapsed in my left arm. This was followed by radiotherapy in April 2016.
50. Since my diagnosis and treatment for breast cancer I suffer from lymphedema in my right arm. This causes puffiness in my arm and wrist and gives me some discomfort.
51. I then received Herceptin treatment on the 23/2/16 to 7/2/17 which is injection treatment for breast cancer to help to stop it returning. I had six echocardiograms to check Herceptin had not damaged my heart. On the 6th April 2016 I started taking tamoxifen, one tablet daily. After this treatment I developed eye problems in the form of drusenoid deposits. These are yellow lumps that appear on the back of the eye. These were detected by my optician on my right eye when I attended for an eye test and I was referred to an ophthalmologist. This condition has not, to date, caused me to suffer any side effects. The yellow lumps are a recognized side effect of the tamoxifen. My doctors advised me that I would need to take tamoxifen once a day for 5-10 years.
52. I do not feel that my infected status had a particular impact on my dental or medical care. I always feel it is important to let all my medical practitioners know that I had the diagnosis of HCV. I informed both my dentist and optician of the diagnosis.

53.

GRO-C

GRO-C

54. The diagnosis of HCV had a huge impact on certain aspects of my private life. It affected my social life greatly. The doctors never told me not to drink, however they always advised me that the recommended minimum 22 units per week was not a guideline I should follow. Rather they said that I should keep below this amount. I had to be careful with my alcohol intake and I felt that I was viewed as boring by my friends and colleagues. I felt that I was invited out less often than before, because I couldn't drink as much as I would have done previously. I now only really enjoy drinking when I go on holiday, maybe twice a year. This is in contrast to my previous habit of enjoying a drink at lunchtime and after work as a young woman. I had to stop that level of social drinking.
55. I did suffer from tiredness and an aching right shoulder however I always thought these symptoms were simply related to my life as a busy parent and normal day to day life.
56. I do recall one particular comment made to me by a family member, which made me feel quite angry. I was open about my infection to my immediate family. Incredibly, one family member told me they would readily have HCV when they learned of the second pay out I had received from the Skipton Fund !
57. The diagnosis of HCV had an impact on my private home life. The biggest impact was the structure of my family as our plan to have children was interrupted according to my treatment needs.
58. My husband had to take time off to attend appointments with me, there were, very few, that he has not been to. He had to make certain sacrifices on his time. I recall that I was reliant on Mark to take me to hospital which was in London and therefore not local to me. I did not

feel confident to drive with my daughter in the car and I needed someone with me at each of my appointments. I needed a second pair of ears to make sure I didn't miss any thing.

59. With regard to my private life we were advised to use condoms during my interferon treatment and my chemotherapy treatment. GRO-C

GRO-C

My mum was unaware of most of what was going on and my family dealt with everything internally. All the family knew I had HCV.

60. In terms of work, I recall that when I was first notified of my infection via a letter I made my immediate team members and manager aware of my situation and the contents of the letter, as I needed to make a phone call to Dr Gorman during the working week to ask questions. I did not wish to delay this and as I needed privacy my team was asked to leave the room so that I could speak without anybody overhearing my conversation.

61. The diagnosis of HCV had an impact on my job and a financial impact on our family. I had not intended to leave work until November but I ended up leaving on the 28th/29th September upon the advice of my Consultant. I had enjoyed my role at Barclays and my departure was therefore premature.

62. I was on maternity leave when Katie was unwell and I lost the chance to apply for voluntary redundancy, because I was busy dealing with her. I subsequently did not go back to work. There was the added strain of my husband losing money and potential contracts when he had to take time off work to attend medical appointments with me. It would be impossible to calculate the actual loss at this point.

63. In terms of stigma I have mentioned the incident with the phlebotomist. Personally my approach was that I had to deal with this. I was relieved to know that the infection had nothing to do with HIV and my mindset

was, that the infection was not fatal right now and I could still have a family. My coping mechanism was not to worry about what was going to happen in the future.

64. When I think about how this condition affected Mark I would say that he viewed his role as supporting me as much as was necessary. I feel that he dealt with stress and anxiety of all the treatment by channelling his energies into being my support system.
65. I knew my mum felt overwhelming guilt for my having contracted this condition and because of this I tried to keep most of my symptoms and stress to myself, I did not want my mum to feel guilty.
66. I know that my son feels emotional at the thought of my being unhappy and in pain. GRO-C he has often questioned whether this could be linked to my infection
67. My own personal guilt lies in the thought that any of GRO-C GRO-C my children have suffered since their birth are related to my infection. Maybe they are more susceptible to illness.

Section 6. Treatment/Care/Support

68. I was never offered counselling or psychological support for my infection and I do not know if this would have been helpful to me. I do think I should have been made to accept some kind of emotional counselling.
69. I have received financial assistance as a result of my being infected with HCV.

Section 7. Financial Assistance

70. I heard about financial support for patients who had contracted HCV when it was raised in the media. Initially I did not think I was eligible for any payment as at the time of my being infected HCV was not in existence. My initial research indicated that I would not be eligible, however I checked google again on another occasion and I found out about the Skipton Fund.
71. I approached the Skipton Fund in February 2016 and they sent me a form to complete, with some explanatory notes. The form contained a section for completion by a medical professional. I asked my GP and Professor Dusheiko at the Royal Free Hospital to fill out the forms. I was required to pay a nominal fee of about £20.00 to my GP. I was informed that Professor Dusheiko had retired and that I should send in the form to Mr Paul Trembling, Consultant in Hepatology. My GP and Professor Trembling were asked to confirm my eligibility for payment, to confirm whether my infection arose indirectly and to confirm that the infection most probably arose through NHS treatment.
72. I had to go through a number of steps thereafter. In April 2016 the Skipton Fund advised me that they had received the completed forms but they needed more information from me. I applied for my birth record/report from Harlow Hospital. The Skipton Fund asked me to prove my identity and address as they had changed from my birth record. I was required to send in proof of marriage and a birth certificate. I found it annoying that I needed to prove my identity and prove that I had suffered the condition.
73. I received a Stage 1 Payment from the Skipton Fund of £20,000 on the 31st May 2016. I was also provided with a form to complete if I wished to apply for a Stage 2 payment. I understood that if you were diagnosed with cirrhosis you were eligible for a Stage 2 payment. The

Skipton Fund requested that Mr Trembling complete another form to provide evidence of cirrhosis.

74. Dr Trembling completed the second stage payment form and wrote to the Skipton Fund to advise them that I had undergone a biopsy on 13th March 1996 which convincingly demonstrated cirrhosis.
75. The Skipton Fund informed Dr Trembling to arrange for me to undergo a Fibroscan to confirm the diagnosis of cirrhosis. Dr Trembling found it quite surprising that they were asking to prove it again. They requested that the Royal Free Hospital arrange this and I underwent the procedure in November 2016.
76. I received a letter dated 24th November 2016 from the Skipton Fund advising me that the sum of £3500.00 would be paid to me on 19th December 2016. This annual payment for Stage 1 recipients included a £500.00 winter fuel payment. I received £3250.00 because the sum was paid on a pro-rata basis.
77. On the 10th February 2017, Dr Trembling sent the Skipton Fund a copy of my original liver biopsy report (1996) and he recommended that I undergo another ultrasound which I proceeded to have on the 6th March 2017.
78. I received a letter dated 30th May 2017 advising me that the Stage 2 lump sum had been approved. I received a remittance of £50,000 on the 12th June 2017.
79. I was also advised that I would receive a Stage 2 regular payment payable from 1st August 2016 to 30th June 2017 which was 11 monthly payments of £1250.00 which came to a total of £13,750.00, less the Stage 1 regular payments already received for this period. I received the balance of £11,000 on the 15th June 2017.

80. I received the following payments from the Skipton Fund; In July 2017 I received £3750.00, in October 2017 I received £3787.50; in December 2017 I received a £505 winter fuel allowance; In January 2018 I received £3787.50; In April 2018 I received £4500.00; In July 2018 I received £4500.00; In October 2018 I received £4500.00; In December 2018 I received a £519.00 winter fuel allowancepayment. I am expecting my next payment at the end of January 2019. The payment scheme has been transferred from the Skipton Fund to EIBSS smoothly.

Section 8. Other Issues

81. I confirm that I have not taken part in any campaigning or litigation in relation to this matter. I also confirm that I am not legally represented and I am happy to give this statement to the Inquiry.
82. I have been asked if there are any questions that I would like to put to the Inquiry and I would like to ask the following questions:
83. Are the recipients of my donated blood traceable and if they are, have they been traced and informed.
84. I would like to know whether I am able to donate my organs it the event of my death. I would also like to know if any checks are carried out before organ donations are made.

Statement of Truth

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

Signed

GRO-C

Dated

11/2/19.