Witness Name: Jonathan Colam-French
Statement No: WITN2736001
Exhibits: 0
Dated: 28th February 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN WITNESS STATEMENT OF JONATHAN COLAM-FRENCH

I, Jonathan Colam-French, will say as follows:-

Section 1. Introduction

1. My name is Jonathan Colam-French. My date of birth is the GRO-C 1970 and I live at GRO-C, Spain with my partner of 30 years, Paul. I am semi retired. Paul and I moved to Spain in April 2017 and we transferred our on-line business of selling soap and candles to Spain. The business is called 'The Dandy Lions'. When I was in England I worked full-time, though voluntarily reduced to an 80% contract for the last 2 years of employment.

2. This 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 or Exhibited to this statement.

Section 2. How Infected

3. I was diagnosed with mild Haemophilia A when I was at primary school so I was about five or six years old. I was adopted as a baby therefore I have no family history. I banged my head which formed a large bump that drained onto my eyes. I was taken to Sheffield Children's Hospital (Sheffield) where tests showed that I have Haemophilia.

4. I stayed under the care of Sheffield from 1976 to 1980 till I was eight or nine years old. In around 1980 a Haemophilia Centre was opened at my local hospital in Lincoln and I transferred to that Centre at around that time. I was under the care of Lincoln Hospital (Lincoln) from 1980 to 1991.

5. I have had two treatments from Lincoln. The first was in April 1982, when I had a bleed in my ankle and was hospitalised for 10 days. Over the course of those 10 days I was treated with Cryoprecipitate and Factor VIII (BPL) batch no. 002943. This number is taken from the Haemophilia Database.

6. I have checked with my father and he has confirmed that I was treated with clotting factors pretty much every day when I was in hospital so I question why only one batch number is recorded.

7. The second treatment was in 1989, again for a bleed to my ankle, though considerably more minor. I had one treatment of Factor VIII (BPL).

8. I attended university from 1988 till 1993 for undergraduate and post postgraduate studies. At the time I lived close to London but remained under the care of Lincoln till 1991 when I transferred to Guy's Hospital in London. This was purely practical from

my perspective as I needed treatment for dental work and it was considerably easier for me to go to London for that purpose.

9. At Guy's Hospital I was treated with Desmopressin (DDAVP) which I responded well to and Tranexamic acid for dental work.

10. In 1993 I moved to Norfolk but from my records it appears that I did not register with the Norwich and Norfolk University Hospital (NNUH) Haemophilia Centre until 1995/6 again as I needed dental treatment.

11. While at the NNUH I received the following treatments:
    a) 1999 – Factor VIII 8Y (BPL) and DDAVP for a liver biopsy; and
    b) 2004 – Helixate and DDAVP for a liver biopsy.

12. The treatments referred to above are the only ones I have ever received for my Haemophilia condition.

13. I have checked with my father and confirmed that no information or advice was provided to him at the time of treatment about the potential risk of infection from blood products.

14. As a result of receiving blood products I have been infected with Hepatitis C (HCV), genotype 3.

15. I was never proactively informed that I had HCV. When I first attended the NNUH in 1998 for an annual check up there was a fair amount of publicity around HCV and I asked whether I needed to be concerned. The consultant was able to confirm from reading my notes that I had indeed been infected.

16. From the medical records I now have I can see that Lincoln tested me for HCV in 1991, but there is no record of the result. The test is mentioned in the referral letter from Dr. Pragnell at Lincoln to Guy's but states that the test results were not yet available. Guy's also tested me in 1993 but at no point did they inform me of the outcome of the test.

17. When I was told I had HCV I was not given any information on lifestyle changes that would have helped me better manage the symptoms. I was never given any advice to understand the infection.

18. I was referred to a Hepatologist for annual check-ups for blood tests for liver enzyme levels but very little information was given about managing HCV. Also the attitude of the consultant was appalling. The NHS had caused my infection but the consultant appeared to have a problem with my sexuality and considered that it was more likely the infection had been caused by my life style. Ultimately I refused to be treated by him, he was an obnoxious man and I was transferred to another consultant.

19. The first test I had for HCV was in 1991, I was 21 and at University doing what 21 year old students do, i.e. I was drinking and partying hard. I continued that way during the first part of my employment career as well.

20. If I had known I was damaging my liver I would have changed my lifestyle. The hospital did not allow me to take responsibility for managing my symptoms, I did not understand at the time why I was so tired, I felt really exhausted and I did not understand why.

21. I was 28 years old when I was told of the infection and I immediately changed my lifestyle. I am now 48 and am fitter and healthier than I was in my twenties.

Section 3. Other Infections

22. I do not believe I have received any other infections as a result of receiving treatment from infected blood. However I did receive a letter from NHS England that I had been placed on the 'At Risk' Register for CJD and that I had to tell my dentist.

23. I have been immunised against Hepatitis B.

Section 4. Consent

24. I do not believe that I have been treated or tested without my knowledge or consent; or for the purpose of research. However whilst I knew my blood was being tested, I did not know what it was being tested for and I did not always receive the results of those tests as highlighted above.

25. I thought my blood was being tested as part of my annual Haemophilia check ups but I did know they were testing me for HIV in the 1980's and 1990's.

Section 5. Impact

26. I was 28 years old when I was told I had been infected with HCV and I became very angry. I lashed out. Paul says I was irrational. I had been living with HCV for 17 years and had not been told. I was living in the GRO-C and after being told of the infection I went into the green house in my garden and got hammered on a bottle of brandy and smoked a packet of cigars.

27. At the time, I was very skinny: I was six foot one inch and weighed 10 stone. I was tired, I had bags under my eyes, I was pale and looked ill.

28. I then changed my lifestyle dramatically and tried alternative medicine from a Chinese Herbalist. He explained that the body stores energy in muscle. I had never

exercised, I did not participate in sport, I had never participated in PE at school as my parents were very protective, due to my Haemophilia.

29. I stopped drinking, started a better diet and enrolled with a personal instructor. I started weight training and went up to 16 stone. I had the diet and the exercise regime of a professional body builder. I would swim 1,500 metres before work. I did all that with HCV and would have started it earlier if I had known I had the infection.

30. I am a different person to who I was in my 20's and 30's. Living with HCV changes your emotions. However, I have managed to change my life around and make the best of it. I am no longer angry; mentally and physically I am far better now.

31. I was told that only when my liver was close to cirrhosis would I be treated with interferon and ribavirin. Also, it was considered that better treatment might be developed that was less arduous than interferon and ribavirin.

32. In 2004, as stated above, I had Helixate and DDAVP for a liver biopsy. The biopsy showed that my liver was close to cirrhosis therefore a six month course of treatment of interferon and ribavirin was recommended.

33. I started the treatment in January 2005 which coincided with receiving a payment from the Skipton Fund. I used the money received to pay for alterative medicine and holidays to get me through the treatment.

34. When I was told of my diagnosis with HCV in 1998 I started having annual check-ups with the Heptologist I was not happy with. The Heptologist just wanted to monitor the liver with liver function tests to plot what was happening to my liver. Between 1998 and 2004 it was a case of monitoring my liver. I had two liver biopsies.

35. When I had my first liver biopsy in 1999 the local health authority refused to treat me with non-human Factor VIII. They did not fund the particular Factor VIII I wanted. I fought long and hard to try to get them to shift their position but I was unsuccessful I had no other choice but to have it with Factor VIII.

36. I thought they were disingenuous to insist on giving me the same product again that had made me ill after only two treatments. In the end I did not have a choice. Over the course of my life I was treated with three treatments from human products and one not from humans.

37. I wanted to receive treatment for HCV when I was diagnosed in 1998. I argued with the hospital, I felt it was better to be rid of HCV as soon as possible; I could not see the point of waiting for my liver to deteriorate before receiving treatment but I did not win.

38. Once I was on the treatment, tests showed that I was clear of HCV at four weeks and I paid for tests at eight and 12 weeks which had similar results.

39. I wanted to stop the treatment as there was evidence that the remaining treatment was not required. But again I did not win the argument and I did not have the courage to stop so I continued for the full six months.

40. I was aware that one local health authority paid for Traditional Chinese Medicine treatment for patients with HCV from a practice run by John Tindall, who is qualified in Chinese medicine. He specialises in people with HCV. I paid privately for treatment with him which I felt was helpful in managing my symptons.

41. I feel there is now a greater openness in the NHS to alternative medicine and other culture's approach to medicine are good. I have no trust in the NHS. I do not go and see doctors I would rather use Google to work out what is wrong with me.

42. I am relatively articulate and intelligent but there are others who have been impacted by this who are not capable of fighting and are ignored by the system, they get passed from pillar to post as they are unable to fight and I find it galling.

43. The treatment I received for HCV was arduous but due to my change in life style, physically the treatment did not phase me. I was very fit, I was able to continue swimming though I did get tired over the last three months of the treatment.

44. The mental impact of the treatment was very significant, I became incredibly depressed, but I declined anti-depressants.

45. When I got to the 12 week point and tests showed I was clear of HCV, I was persuaded to continue with the treatment, I remember it coincided with Easter and I spent the whole of Easter under a duvet, crying my eyes out.

46. At the time I was receiving treatment I was a director of corporate information services at the University of East Anglia. I had 60 people under me. I was also doing an MBA and I was taking part in a higher education programme, a top management programme and was on track for significant roles in management.

47. Due to the treatment I had to defer the second year of the MBA and the top management programme, all I could manage at the time was work and keeping up my fitness levels I could not manage anything extra.

48. However I did return to the MBA a year later and the top management programme six months later as the course was run twice a year.

49. I do not believe my HCV has impacted upon my treatment, medical and or dental care for any other conditions, though it is difficult to de-couple it from my Haemophilia. However, I do not know if it was as a result of my HCV or that I am on the CJD at risk register that when I go to the dentist I am always given the last appointment of the day so that as soon as I have left the practice they could super sterilise everything.

50. My condition has had a huge impact on my partner, Paul. We have been together for 30 years since we were 18. It has been incredibly difficult though socially the impact has been negligible.

51. My father blamed himself for allowing it to happen to me and he feels very guilty. But overall I feel the impact could have been worse.

52. I have never been secretive about having HCV or Haemophilia so the stigma has not arisen and I do not feel it has affected my career prospects. By the age of 26/7 I had achieved a relatively senior position and people do not tend stigmatise as it would not get them anywhere.

53. I also do not think my HCV has effected my education but it is difficult to tell. When I did my degree I had had HCV for seven years. I have three degrees, a 2.1 in maths, a masters in computer science, and an MBA. Perhaps I might have achieved a 1st if I had not had HCV.

54. I believe the HCV did impact on my personality. Before I knew I had it I was angry, I had few friends socially or at work. Having the virus shaped my personality.

55. I am very different now to when I had HCV. The last few years at work in England after my HCV had cleared my approach to work was different, my work/life balance

changed. Things stopped being overwhelming difficult and the World is a much better place having cleared HCV.

56. I think HCV has impacted on all aspects of my life and career but it is impossible to quantify it.

57. GRO-B GRO-B consider semi-retirement at the age of 46.

58. I have now given up work to live in Spain though I do have an on line business selling soaps and candles which I transferred from England to Spain.

59. But for the HCV I may have continued my career in England and been very driven. I now have a better quality of life but I do not think I would have done that but for my HCV and the interferon.

Section 6. Treatment/Care/Support

60. I have never been offered counselling or psychological support. It might have been helpful particularly at the start of my treatment with interferon and ribavirin.

61. I created a blog and I wrote every day about my treatment as to how it made me feel. There were others also blogging about their experiences and as a result an informal support group was created. There were 12 of us writing and a number of people reading them; it was very supportive.

62. Having the blog got me through the treatment. A man called GRO-A started it and his blog was linked to the BBC website and was picked up by a BBC producer who took four of the blogs and turned them into a play for Radio 4. I received some money for my contribution.

63. I feel counselling or psychological support would have been helpful as it was invaluable to me in my early 20's when I was tracing my natural parents. It would have been helpful to talk to people and get a better understanding of the situation that I found myself in.

Section 7. Financial Assistance

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Section 8. Other Issues

74. Haemophilia is a disorder that predominately affects men and yet when I have attended a Haemophilia Centre all the consultants were female. I believe that this is wrong.

75. I also believe that more support could and should have been provided a lot earlier, when I was younger and when I truly needed it.

76. I believe that in my case it all revolved around sexual health and sexual orientation and on occasions the actual source of my HCV and seriousness of the problem of how I was infected was downplayed.

Anonymity, Disclosure and Redaction

77. I confirm I do not wish to have anonymity and that I understand the statement will be published and disclosed as part of the Inquiry.

78. I do not wish to be called to give oral evidence to the Inquiry.

Statement of Truth

I believe that the facts stated in this Witness Statement are true.

Signe GRO-C

Jonathan Colam-French

Dated: 28th February 2019