

Witness Name: N Jones

Statement No: WITN1756001

Exhibits: WITN1756002

Dated: October 2018

## INFECTED BLOOD INQUIRY

---

### FIRST WRITTEN STATEMENT OF NICOLA JONES

---

I, Nicola Jones, will say as follows:-

#### Introduction

1. My name is Nicola Jones (nee Enstone). My date of birth is GRO-C1970 and I live at GRO-C Herts GRO-C with my husband, Paul, and two children. I currently work for an ambulance provider in an office based role. I have been in this role for about 3 years.
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.

#### How Infected

3. My father is a haemophiliac and when I was 7 I was told that I was a haemophilia carrier A with low Factor VIII level. When I was diagnosed I was told I was not a haemophiliac because haemophilia is a "male" disease.

4. Initially my parents were told that I would need treatment to help with clotting. I was treated with cryoprecipitate at the Haemophilia Centre at the Royal Free Hospital in London. My father was under the same centre and had received the same treatment. However, my treatment was subsequently changed (without my knowledge) to Factor VIII in 1980. I was given Factor VIII in 1980 (tonsillectomy), 1981 (right forearm muscle), 1992 (left elbow joint) 1993 genito-urinary) and 1995 (left ankle joint).
5. I only discovered this fact in or about 2002.
6. I have a tonsillectomy in May 1980. I was treated with Factor VIII concentrate prior to and following the surgery (on 6 and 7 May 1980). At the time of my surgery I was under the overall care of Eleanor Goldman at the Haemophilia Centre at the Royal Free Hospital. I was under the care of John Win, Registrar, for the tonsillectomy.
7. This was the first time I was given Factor VIII. The letter from The Royal Free confirming this also states that I should have been reviewed at the Haemophilia Centre on a 2 weekly basis for liver function tests. The Centre have since accepted their failings in that these tests were never carried out.
8. I was infected with Hepatitis C as a result of being given contaminated Factor VIII blood products at the time of my tonsillectomy on 6 May and 7 May 1980.
9. No advice was given to me or my parents at the time about the use of or risks associated with blood products. I recall when I was a child a doctor would walk in to my room, inject something into my drip and then leave without saying anything. We were not even told about the change in my treatment. I did not find out about this until years later although it is clearly documented in my medical records that I was given Factor VIII no one discussed it with me or my parents.
10. From about 1980 (when I was 9 years old) my mother noticed that I had changed from an average, healthy young girl who enjoyed doing all sorts of

activities, to a girl who suffered poor health, took to her bed, became overweight and generally complained of being unwell.

11. I attended St Michael's School in Garston and when I came home from school I would go straight to bed because I was so tired.
12. In 1981, a year after the tonsillectomy, I was admitted by the Haemophilia Centre to a children's ward at the Royal Free Hospital for the 6 week summer holiday because my mother had raised concerns about my deteriorating health and increased weight. I was told this was to put me on a diet of 500 calories a day and that I would be a new child, a slim young child again. I was put on a 500 calorie a day diet and went swimming and walking with the nurses. I walked up and down the 12 flights stairs of the hospital every day to lose weight.
13. At the end of that period I had only lost a few pounds and the doctors accused my parents of smuggling in food (which was not the case).
14. During this period at the hospital I was seen by Dr Eleanor Goldman, Associate Specialist, and a paediatrician named Francis Howard (Locum Paediatrician). Aside from a letter from Francis Howard, I have never seen anything in my medical records relating to this extended stay in the hospital.
15. I was taken to the Haemophilia Centre at the Royal Free numerous times by my mother who was determined that there was something wrong. I remember that the doctors used to put off seeing her and when they did see her they told her it was all in my head and psychological.
16. My school work deteriorated because I could not concentrate. It is clear from my medical records that my school contacted Hertfordshire County Council School Psychology Service because they were concerned about my progress. I felt tired all the time. I would rather sleep than eat and yet I kept putting on weight.

17. In 1984 I was tested for HIV. I was 13/14 years old and Dr Goldman at the Haemophilia Centre told me about the virus and why I was being tested. She explained that some of the treatment they were giving people had been infected with HIV, and although I probably wouldn't have it, they needed to run the tests anyway. My parents were never told or consented to this test, and it was just me, Dr Goldman and a social worker, Reeva Miller, present in the room. My father was also tested and luckily both our tests came back negative.
18. I continued to struggle with my health. I had aches, pains, rashes, bloating. I felt tired and sleepy and slept when I could. I do not feel much has changed in that regard.
19. My mum remained concerned about my health and in or about 1985 took me to the Haemophilia Centre at the Churchill Hospital in Oxford for a second opinion. They also said that there was nothing wrong. She has since told me that she felt uncomfortable. There was never any follow up from the appointment.
20. When I left school in 1989, I got a job at Hill End Hospital as a nursing assistant dealing with mental health patients. I continued to sleep when I could. It was more than just normal tiredness. I felt drained all the time, like the life had literally been sucked out of me. I have been in pain daily for most of my life and this increased after I had breast cancer in 2010.
21. In 1992 I had a recorded transfusion reaction (bronchospasm and facial flushing) to Factor VIII concentrate (batch number FHB 4108). This was the same batch I had been given on two previous occasions.
22. In 1995 my mother was watching the television when she saw that there was a new strain of Hepatitis that was killing many people although it mainly affected haemophiliacs. It was called Hepatitis C. When the news listed the signs and symptoms of the disease, such as weight issues and tiredness, my mum immediately thought of me.

23. My mum rang me and told me what she had seen. At the time I was being treated at the haemophilia centre for an ankle bleed and she said that I should ask them to test me for Hepatitis C as I had all the signs and symptoms. Before this I did not even know there was a Hepatitis C, I was only aware of Hepatitis A and B.
24. When I attended the clinic for my treatment and asked the nurse treating me if I had ever been tested for Hepatitis C she laughed at me and said "you won't have that". Then she got my medical records and told me that I had tested positive for the disease in 1991.
25. I was seen by Dr Eleanor Goldman either the same day or the following day and she confirmed what the nurse had told me - that I was Hepatitis C positive. However, she told me not to worry about it as they did not know much about Hepatitis C and it may not affect me for another 20 years or more. She also told me to think myself lucky that I was not positive for HIV.
26. There is a letter in my notes dated 20 March 1997 which confirms I was given unsterilized Factor VIII on 5 June 1980 (the date is incorrect and should read 6 May 1980) and therefore that I would have been infected with Hepatitis C but that my transaminase levels performed on 14 July 1995 showed a normal AST of 13 u/l and an ALT of 18 u/l. This letter was written after I went to see my GP because I needed a letter to support my nursing application.
27. I did not think much about the diagnosis at the time other than that it explained why I felt the way I did. I was relieved that I finally had an explanation for the years of illness I had suffered.
28. In 2004 I wrote to The Royal Free to obtain information needed to make a claim from the Skipton Trust as my GP had advised me to apply to the fund. Following a review of my notes I was told that the first record of antibodies to Hepatitis C in my blood was in 1995 when the antibodies were weakly positive. The letter states that I was not tested for the virus itself until November 1998 when the blood test result came back negative. The letter

stated that it was likely I had been infected with Hepatitis C at the time of my first infusion with large pool clotting factor concentrate and that approximately 15% of people infected with Hepatitis C cleared it naturally so I was one of the fortunate people who had not had an ongoing Hepatitis C infection.

29. There are notes in my hospital records from the Haemophilia Centre at the Royal Free dated 22.09.92 which state that my anti HCV should be repeated – these investigations were not discussed with me. As stated previously, I was not aware that I was being tested for Hepatitis C.

30. My medical records are not complete. There is no reference to my 6 week stay in the summer holidays. There is one line in my notes dated 8 August 1990 where Dr Goldman has written “discussed Hepatitis C”. This did not happen. I was entirely unaware of the infection until 1995 as described above.

31. I used to go to the Dentist at the Royal Free Hospital and whilst I was waiting for my appointment I would sit reading my notes. This was when I found the result stating I had tested positive for Hepatitis G. I first saw this note in my records around 1995, and in 2009 I decided to take a picture of this page. The blood test result is dated 1980 and 1992. I have since received copies of my medical records from The Royal Free and this document was not in the copy they provided me with, despite the fact I have seen that it is still in my notes at the hospital. I rang the Haemophilia Society for support and was told not to worry about it. A copy of this record is exhibited to this statement as **[WITN1756002]**.

32. I never raised this issue with anyone at the hospital as I was so used to being shut down and disregarded by the doctors whenever I had a problem.

33. The letter which Prof Tuddenham wrote to the Skipton Fund in 2010 (4 October) states that in or about 1982 (2 years after my tonsillectomy) the Centre discovered that I had become Hepatitis C antibody positive but that I was not producing detectable hepatitis RNA and my liver functions were

normal by that time. The copy of the notes I have been provided with does not contain any references/tests which are consistent with this and I do not know where this information has come from.

### **Other Infections**

34. In 2004, when I was 5 months pregnant with my son, I received a letter in the post from the Department of Health which told me I was at high risk of vCJD and that I was on the "At Risk" register so I needed to declare to dentists or others if I was going to undergo any operations. I said to my husband that it was just another thing to add to the list and put the letter in a drawer.

35. I received a letter from the haemophilia centre saying that I had received treatment from someone who had died from vCJD. The letter enclosed a list of batch numbers. These meant nothing to me and again I put the letter in a drawer. The risk of vCJD was never discussed with me by my treating doctors at the Haemophilia Centre.

36. In 2013 there was media coverage which suggested haemophiliacs had also been exposed to Hepatitis E so I asked my GP to be tested. The test came back negative.

### **Consent**

37. No one had told me that I was being tested for Hepatitis C in 1991, let alone that the test had then come back positive until I found out in 1994. Whenever I had blood tests I was always told that it was to check my Factor VIII levels. I had been advised about testing for HIV and Hepatitis B had previously been mentioned to me as I was given a vaccination for it (I was told that they were vaccinating everyone) but Hepatitis C had never been mentioned.

38. As addressed above, my parents were not aware and therefore could not consent to me being tested for HIV when I was 13/14 years old.

### **Impact**

39. I used to be an extremely social and outdoorsy child. I enjoyed school and was always extremely active, riding my bike to the park with friends and going horse riding. However this all stopped when I was 9 years old after being treated with Factor VIII. I lost all of my energy and would stop going out or seeing my friends as I was always so tired. When I was old enough to get the bus to school by myself, I would frequently skip school so I could come straight home to sleep. As a result, my grades suffered and I struggled academically.

40. By the time I was 16 most of my teeth were crowned because of the deterioration in them. Later I was told by a nurse at the Haemophilia Centre that research was being done into whether there was link between the use of concentrate and dental problems. The loss of my teeth has impacted hugely on me throughout my life because it is what people look at when you speak. It has certainly impacted on my mental wellbeing. It has knocked my confidence and dentists are reluctant to treat me having suffered from Hepatitis C and haemophilia. I worry about the next crown falling out and what I will do then.

41. I left school at 16 with 4 GCSEs in typing, maths, English and Religious Studies and became a Nursing Auxillary in Hill End in 1988 before doing a couple of years work in a nursing home.

42. I joined the ambulance service at the age of 21.

43. Even now my social life is non-existent. I do have friends but I struggle to go out or do anything with them because of my current condition.

44. My condition has seriously impacted my role as a mother. There are many family activities that I cannot participate in and if I do make it to our family



outings, it takes me a long time to recover from them physically. This has been the case since when I was young.

45. I am very sceptical of health professionals now, but having worked in the industry myself I am now better at communicating with doctors, with the exception of those at The Royal Free. I feel that having had the experience I have had and having lost trust in the medical profession it has made me stronger in advocating for service users in my job. However the experience has made me more wary of going to the doctor.

46. I need to take painkillers daily. Initially I took co-proximal, before being prescribed co-codamol. This has since been replaced with dihydrocodeine.

47. When I was younger I wanted to be a hairdresser, however it is something I could never realistically work towards as I would not be able to spend that long on my feet.

48. Whilst I was working at Hill End I was off work fairly regularly due to my condition. In my job managing a care home, I was fortunate that the care home was owned by my brother who helped to ensure that my workload and the physical elements of the job were manageable. I have been working for an ambulance provider for 3 years now, which I find easier as it is office based.

49. In 2003 I went for a standard eye test and the optician at Specsavers told me that I had a lesion on my eye (right on the artery) and referred me to Moorfields. When I was seen at Moorfields they said it could have been caused by a virus or it might be Von Hippel Lindau syndrome which is a hereditary condition. I had genetic testing at St George's in Tooting and this ruled out Von Hippel Lindau syndrome. I am still monitored for any changes in the lesion on a regular basis by my optician.

50. My children are both affected with bleeding disorders. My son is a haemophiliac and my daughter is a carrier and has a platelet disorder. In 2013 I requested a letter from Great Ormond Street Hospital in relation to my son because we were going on holiday to Cyprus and always require a letter to get through customs with the relevant needles and treatments. In this

letter, I saw that my son had been tested for HIV and Hepatitis. I was shocked to discover this as I had never consented to (or indeed been asked to consent to) such testing.

51. I reported this incident to the police who documented this as a serious assault on a minor due to the testing being undertaken at a London Hospital. They referred the case to the Metropolitan Police who were not interested and simply told me to complain to the hospital. I did not do so as I was concerned about making a complaint to the hospital that continues to treat my children.

52. I also reported the incident to the local safeguarding team at Hertfordshire County Council. They told me that there was nothing they could do because it had happened in Hospital. Neither the CQC or the Haemophilia Society were any help. I then also discovered that my daughter had had similar testing without consent since birth.

53. I have only ever been informed of The Royal Free (where they were initially treated) and Great Ormond Street taking blood to check my children's kidney function, for platelet disorder and on one occasion for inhibitors. These are the only tests at Great Ormond Street that I was informed about and consented to.

54. In 2017 Andy Burnham wanted to hear from people affected by the Contaminated Blood Scandal so I emailed his office explaining about what happened to me and that my son had been tested for HIV and hepatitis without my consent (I was not aware at that stage that my daughter had also been tested). He texted me to ask to call me and he called me personally and said that he was shocked to hear about the non consensual testing of my child and would he mind if he spoke about my case if he had the chance in Parliament. I gave permission and spoke about my case and a number of others on GRO-C 2017 in support of the ongoing quest for a full inquiry into the scandal.

55. I have struggled with my health for years. Since about 2001 I have had progressive elevation of autoimmune antibodies accompanied by symptoms consistent with collagen vascular disease. Initially the doctors at Queen Elizabeth II hospital suspected I was suffering from Lupus, before it was 'downgraded' to an autoimmune disease. Professor Edward Tuddenham, Director of the Haemophilia Centre and Thrombosis Unit at the Royal Free Hospital confirmed (in support of my application to the Skipton Fund) that he considers this is attributable to the Hepatitis C infection I acquired from the infected Factor VIII blood product.
56. I was diagnosed with breast cancer in 2010. I received treatment at St Albans Hospital by way of lumpectomy and gland removal. I had post operative radiotherapy and was prescribed Tamoxifen. I have been clear of breast cancer for 8 years now.
57. In 2015 I asked for a referral to St Thomas' because I had lost faith in the Royal Free. The Royal Free told me that they could not carry out a fibro scan on my liver because I was too fat and did not offer to refer me anywhere else to have it carried out. My GP referred me to St Thomas' and they were able to carry out the scan which was normal. However, they did find that my Factor VIII level was lower than the Royal Free had recorded.
58. I feel like I have been lied to and ignored by various public health bodies in an attempt to silence me. I also believe I have been singled out because I was female (and the medical profession considered haemophilia a male disease) and someone who didn't require much treatment. I find it unacceptable that the unethical behaviour that I experienced has now carried on with my children. It feels like history repeating itself.
59. I have been unable to obtain private healthcare or life insurance because of receiving infected blood products. I have tried over the years but when you have to declare that you have had Hepatitis C and are at high risk of CJD the insurance companies simply don't want to know.

## **Treatment/Care/Support**

60. I have not had any specific treatment for Hepatitis C because I have been told that I naturally cleared the infection. My GP was a homeopath as well as a GP and in 1998 he prescribed me a homeopathic remedy for Hepatitis C. He was never convinced that I had cleared the infection particularly given the positive test results in 1997/8. As no liver function tests were done following my tonsillectomy it is unclear when exactly the infection cleared.
61. I have thought about having counselling at times over the years and made initial enquiries about this at one stage but was never followed up. I feel as if I have some form of PTSD because of what I have been through.
62. In approximately 2014 I was diagnosed with a benign essential tremor, which I believe has been brought about by the stresses over the years of dealing with contaminated Factor VIII
63. One thing that has helped me enormously is finding and making contact with Tainted Blood. I first found them on the internet and contacted one of the administrative staff there who put me in touch with Mark Ward.. Speaking to him over the years has kept me sane and I couldn't believe that he was also being treated at the same centre as me.
64. It was only through talking to Mark that I discovered I had been swapped onto Factor VIII at the time that my health deteriorated because he encouraged me to get hold of my medical records. My parents and I were never told about the change of treatment.

## **Financial Assistance**

65. When the Skipton Fund was announced in 2004 my GP advised me that I should apply. He completed the paperwork and I was turned down for any financial assistance on the basis that, on the balance of probabilities, I had cleared the Hepatitis C virus within 6 months.

66. Despite the fact that there is are positive Hepatitis C ELISA result referred to in my records in 1997 and positive antibody by EIA results in 1995, 1997 and 1998 , the Skipton Fund concluded I would have cleared the infection by 1980 (6 months after infection). They concluded that the doctors got it wrong and the 1997 test must have been wrong as well. I was only tested for the Hepatitis C virus itself in 1998 and that test came back negative.

67. Furthermore, despite the findings of the Penrose Inquiry that 70% of people who received these products will go on to receive cancer, when I approached the Skipton Fund after my breast cancer diagnosis I was informed that this was the 'wrong type' of cancer.

68. Professor Dusheiko was a director of the Skipton Fund. He worked closely with Professor Lee at the Royal Free and did a number of research papers on haemophiliacs with Hepatitis C. I felt that Professor Lee did not support my application to the Skipton Fund because I had cleared the Hepatitis C naturally and I also felt that there was a conflict of interest in Professor Dusheiko being involved in the Fund at a high level. I raised this with the Department of Health at the time and asked what safeguards had been put in place. I did not receive a response for about 3 months and when I did they said they could assure me that safeguards had been put in place but they did not provide any specific information.

### **Anonymity, disclosure and redaction**

69. I confirm that I do not wish to apply for anonymity and that I understand this statement will be published and disclosed as part of the Inquiry.

70. I want to provide oral evidence to the Inquiry.

**Statement of Truth**

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

Signed GRO-C .....

Dated 2/11/18 .....

## MEDICAL SUMMARY

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

### Treatment Record

06.05.1980	VIII Conc-NHS	Batch: HL2666	(Tonsillectomy)
07.05.1980	VIII Conc-NHS	Batch: HL2666	(Tonsillectomy)
08.05.1980	VIII Conc-NHS	Batch: HL2666	(Tonsillectomy)
16.11.1981	VIII Conc-NHS	Batch: HL2842	(Rt Forearm Muscle)
30.08.1992	BPL 8Y	Batch: FHB4108	(Lt Upper arm Muscle)
02.09.1992	BPL 8Y	Batch: FHB4108	(Lt Upper arm Muscle)
09.09.1992	BPL 8Y	Batch: FHB4108	(Lt Upper arm Muscle)
17.09.1992	BPL 8Y	Batch: FCH4117	(Lt Upper arm Muscle)
18.09.1992	BPL 8Y	Batch: FCH4117	(Lt Upper arm Muscle)
20.09.1992	BPL 8Y	Batch: FCH4117	(Lt Upper arm Muscle)
22.09.1992	BPL 8Y	Batch: FCH4117	(Lt Upper arm Muscle)
08.11.1992	BPL 8Y	Batch: FCH4117	(Lt Elbow Joint)
18.05.1993	BPL 8SM	Batch: FHR4037	(Genito-urinary)
07.07.1995	BPL 8SM	Batch: FHR4325	(Lt Ankle Joint)

08.07.1995	BPL 8SM	Batch: FHR4325	(Lt Ankle Joint)
09.07.1995	BPL 8SM	Batch: FHR4325	(Lt Ankle Joint)
12.07.1995	BPL 8SM	Batch: FHR4325	(Lt Ankle Joint)
14.07.1995	BPL 8SM	Batch: FHR4325	(Lt Ankle Joint)
18.07.1995	BPL 8SM	Batch: FHR4325	(Lt Ankle Joint)

Virology Results

**No evidence in the records of any testing for Hepatitis C prior to 1995.**

17.08.1992	Hep B negative (no Hep C test)	
21.04.1994	Hep B tested (no Hep C test)	
14.07.1995	Hep C Ab by EIA	Weakly positive
	Hep C Ab by RIBA	Indeterminate
	HIV negative	
12.03.1997	Anti HCV ELISA	Positive
	Final HCV result	Positive
02.04.1997	Hep C Ab by EIA	Weakly positive
	Hep C Ab by RIBA	Reactive
	HIV negative	
06.07.1998	Hep C AB by EIA	Positive
12.11.1998	HCV RNA not detected	
04.11.1999	Hep A and B tested but not Hep C	



09.01.2001            Quantitative HCV RNA not detected

02.03.2004            Anti HCV reactive. Please send follow up samples to determine possible rise in EIA reactivities which would suggest recent acute HCV infection.

08.04.2004            Microbiology/serology  
Hepatitis C Antibody test: Positive  
Anti HCV Ortho: Reactive  
Anti HCV Biorad: Reactive  
Anti HCV status:    Reactive  
Please send follow up samples to determine possible rise in EIA reactivities which would suggest recent acute HCV infection.

02.04.2004            HCV RNA:    Not detected  
Serological profile consistent with past and not ongoing HCV infection.

25.04.2006            Microbiology serology  
Anti HCV (Ortho EIA)        Reactive  
Anti HCV (Biorad EIA)        Reactive  
Anti HCV status                Reactive  
HCV RNA                        Not detected  
Serological profile consistent with past but not ongoing infection.

10.08.2006            Hep C igG Ab        Positive – consistent with Hep C infection.  
No Hep C RNA was detected.

12.06.2013            Hepatitis E antibody level – satisfactory no action

03.03.2014            Hep C AB test positive

08.09.2014            Hep C Ab test Positive

28.07.2015 Hep C Ab test Positive

Significant Entries/Absent Entries

21.09.1978 tooth extracted under Cryoprecipitate cover.

06.05.1980 Treatment changed from cryoprecipitate to Factor VII. No evidence of any discussion with the patient or her family.

1980 Positive result for Hepatitis G (also dated 1992). **Not provided to the patient in her copy records.**

29.07.1980 Letter from F Howard, Locum Pediatrician. Saw Nicola in clinic on 17.07.80.

Summer 1981 **No entries at all in hospital records in relation to the 6 week in patient stay which the patient refers to in her Statement.**

16.11.1981 **No treatment records for the right forearm muscle.**

08.10.1982 Redness and swelling around the foot following removal of a wart. Thought to be masked infection with lymphatic spread. One week course of Erythromycin recommended.

1984 **No entries at all in relation to the patient being HIV tested as referred to in her Statement.**

08.08.1990 Note of review with Eleanor Goldman. States: "*discussed hepatitis C*". **This was not discussed.**

23.08.1990 Letter from Dr Goldman. Routine blood tests were normal. Tests for anti HIV, anti HCV and HBsAg were negative.

- 01.10.1990 Letter from Royal Free to GP. Nicola has had a tooth extracted with cover from DDAVP. The following day she re-attended feeling unwell and tearful. She is convinced that DDAVP makes her unwell and states that she does not wish to have this treatment again in future.
- 07.10.1991 Elective tooth extraction at Royal Free. Complained of generalized neck, chest, back and abdomen pain. Consider it is likely to be related to the anaesthetic. Don't think it is related to the haemophilia or infusion of DDAVP.
- 30.08.1992 Clinical notes in relation to left arm.
- 09.09.1992 Letter from St Albans City Hospital to GP. *"This 21 year old ambulance lady with known Van Willerbrands Disease under the care of Dr Lee at the Royal Free....."* Believed to have suffered an idiosyncratic response to her Factor 8.
- 17.09.1992 Letter from Royal Free to GP. Treatment following injury to left elbow. Suffers from an idiosyncratic reaction to most therapeutic agents including DDAVP and Factor VIII concentrate. During this reaction she suffered from facial plethora and acute broncho spasm.
- 20.09.1992 *"If the patient does NOT have an already known chronic viral infection, please arrange a repeat test for lymphocyte subsets in 3 months time."*
- 20.09.1992 Clinical notes. Investigations – repeat anti HCV. **This testing was not discussed with the patient.**
- 12.10.1992 Letter from St Albans City Hospital re patient's adverse reaction to Factor VII. The Factor VII was NHS which is apparently of intermediate purity. They (the Royal Free) are conscious of the

problem. They are going to give her any further concentrates under medical supervision....They have filled in the Adverse reaction form but feel it is going to be difficult to identify any particular aspect that caused this problem as Nicolas has previously had this strength Factor VIII with no trouble....I have asked Dr Gaminara for advise about the contents (of the Factor VIII).

- 11.11.1992 Immunology results. Hand written note "I think we don't see any evidence for connective tissue disorder."
- 27.11.1992 Letter from St Albans City Hospital. Nicola has had 2 further courses of factor VIII with hydrocortisone and chlorpheniramine cover. On the second occasion she had a mild reaction necessitating further treatment....Nothing new to add to her management.
- Jan 1993 Referred to the Churchill Hospital, Oxford by GP in respect of left arm.
- 18.05.1993 **No treatment records in relation to treatment for the pre op or operation.**
- 20.02.1995 Letter from Dr Clements, Consultant Physician & Endocrinologist, BUPA to GP. GP referred patient for chronic fatigue and morbid obesity. Patient's mother thought she might have hypoglycemia or hypothyroidism. No organic cause found for the patient's complaints of sleeping, feeling tired and slow. Advised that her fatigue was constitutional in origin.
- July 1995 **No treatment records in relation to treatment for the left ankle joint.**

- 26.07.1995 Review with Eleanor Goldman. Injury to left ankle 4/7/95. Treated with DDAVP x 3 – no improvement. Treating with 8SM x 5 with good effect. First treatment with Factor VII since 1993. General health good. ....HIV neg. HAV for vaccination today (because HCV pos.). HBV vaccinated. HCV pos. Discussed transmission and progress.  
Plan: Review 1 year.
- 03.08.1995 **Copy of letter on GP records only – not on Royal Free notes.**  
Letter from Royal Free to GP. *"We discussed hepatitis C in some detail. She appeared to be well informed. Tests for hepatitis C have regularly come up weakly positive by EIA and indeterminate for RIBA. However, I think that we have to consider her to have been infected with hepatitis C, since everyone treated with blood products prior to 1985 has been found to be hepatitis C positive. She understands this.*
- 20.03.1997 Letter from the Royal Free confirming unsterilised Factor VIII given on 5 June 1980 (**the date is incorrect – it should read 6 May 1980**) and that the patient would have been infected with Hepatitis C but that transaminase levels on 14.07.95 showed normal AST and ALT.
- 14.04.1997 Letter from Royal Free (**not in hospital records**). Nicola did have a specimen taken on 2<sup>nd</sup> April and it has been tested in the Virology Laboratory for PCR for hepatitis C virus. The PCR was negative. Thus, I think we can really begin to conclude that this patient has largely cleared hepatitis C infection.
- 25.02.1998 GP prescribes acute homeopathic prescription – Hepatitis C nosode 30 c weekly.

24.01.2001 Letter from the Royal Free. She is hepatitis C PCR negative and I enclose the results we have showing that. She has run consistently normal transminases and she belongs to a small percentage of our patients that is 10% who have cleared hepatitis C naturally. I can confirm that she is no longer infected with hepatitis C and has immunity to it.

01.03.2001 Letter from GP to Professor Lee. *"I did give my patient an isopathic prescription (similar to homeopathy) of Hepatitis C Nosode 30C 1 tablet weekly from 25 February 1998 which I believe she continued for several years.....Certainly Nicola felt very much better soon after starting the Hepatitis C Nosode therapy but of course it may just be a coincidence that she seems to have cleared the Hepatitis C antigen naturally."*

09.12.2004 Letter from Royal Free confirming first record of antibodies to hepatitis C was in 1995 when the antibodies were weakly positive. Confirmed patient was not tested for the virus until November 1998 and that test was negative.

*"It is likely that you will have been infected with hepatitis C at the time of your first infection with large pool clotting factor concentrate. We know that approximately 15% of people who were infected with hepatitis C cleared this naturally and you are one of the fortunate people who have not had on ongoing hepatitis C infection."*

28.04.2005 Letter from Endocrinologist to GP. Dr Johnston saw her at the end of December 2003 during her pregnancy with chronic fatigue and elevated inflammatory markers....Feeling of a muzzy head and being spaced out and says things are distant from her. This is worse in the mornings although she can also suffer the afternoons...CRP 20.5 and ESR 27. These are not nearly as elevated as they were in 2003.

- 17.02.2006 Endocrine clinic. Persistent tiredness. Persistent mild elevation of inflammatory markers. Has felt like this for 10 years.
- 24.04.2006 Liver scan showed inflammation.
- 17.08.2006 Letter from Dr Patch (Consultant Physician & Hepatologist) at Royal Free to GP. *"Thank you for referring this 35 year old with mild haemophilia A, who is apparently Hepatitis C +ve (there were no results on the PAS system at The Royal Free).....I have requested HCV PCR (I wonder whether one of the reasons this lady may not have been treated was that she was antibody positive, but PCR negative)....The decisions on treatment will be dependent on whether there is evidence of circulating virus. Certainly her liver function tests appear normal."*
- 14.11.2006 Letter from Dr Patch to GP. Patient's repeat HCV PCR is negative...no further action is required.
- 03.09.2007 Question of whether she developed lupus. On examination no hard evidence of any connective tissue disease. ESR has been raised for many years.
- 12.08.2008 Letter from Consultant Rheumatologist to GP. Main problem is fatigue and tiredness. This is associated with various aches and pains and headaches. Her ANA is significantly positive. Double stranded DNA is negative. Her ESR is slightly up at 35 and CRP 21.
- 09.12.2008 Letter from Consultant Rheumatologist to GP. Improvement in symptoms. Non specific symptoms with itchy skin, fatigue and aches and pains. These have almost completely gone.

25.12.2009 Letter from Consultant Rheumatologist to GP. Undifferentiated connective tissue disorder. Low grade inflammatory problem for a number of years. She has just been told that in 1992 she probably had hepatitis C. Clearly she has treated herself and is not a carrier now. Her liver function is fine. However hepatitis C can certainly trigger immune problems. Her ANA remains persistently positive but no really showing any particular connective tissue disease....She can control most of her symptoms with painkillers. She is clearly also upset about what has happened in the past.

August 2010 Diagnosed with breast cancer.

20.07.2011 Letter from Royal Free. No stored samples in the laboratory from that time so we have no way of carrying out any additional tests. This is because of the length of time that has passed and the fact that samples are not stored indefinitely. **(No copy in Royal Free notes)**

26.06.2012 Letter from Consultant Rheumatologist to GP. Review. Still suffers from fatigue, aches and pains.

02.01.2013 Letter from Consultant Rheumatologist to GP. Mrs Jones sadly continues to have severe problems. Her main symptoms are fatigue and stiffness. This has obviously been present for a number of years but it does seem that since she started taking tamoxifen 2 years ago her symptoms have deteriorated.

20.03.2014 Letter from GP to Royal Free requesting second opinion re patient's back pain as her relationship with St Albans City Hospital had broken down.

23.04.2014 Letter from Consultant Rheumatologist to GP. Fatigue still a major problem. Connective tissue disease in remission.



- 16.12.2014 Letter from Consultant Rheumatologist to GP. September blood test results show no evidence of a connective tissue disease....Therefore she has a sleep deprived fibromyalgia problem.
- 03.06.2015 Referral from GP to Haemophilia Clinic at St Thomas' Hospital asking for a second opinion on patient's haemophilia.