

Witness Name: Sean Philip Nevin

Statement No: WITN1425001

Exhibits:WITN1425002

Dated: January 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF SEAN PHILIP NEVIN

I, Sean Philip Nevin will say as follows:-

Section 1. Introduction

1. My name is Sean Philip Nevin. I was born on [GRO-C] 1969 and I live at [GRO-C] [GRO-C] Merseyside, [GRO-C] with my wife and 2 sons.
2. My sons are aged 19 and 17 but both still live at home. My wife works full time. I am currently unable to work as a result of my medical condition.
3. I was infected with Hepatitis B and Hepatitis C (genotype 1A) from contaminated blood products.
4. 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.

Section 2. How infected

5. I was diagnosed with mild haemophilia A (clotting factor 5%) when I was 10 years old. Prior to this I had already suffered several injuries, including two heavy blows to the head, which had healed without the need for Cryoprecipitate or Factor VIII.
6. I have always been treated at the Roald Dhal Centre at the Royal Liverpool Hospital (RLH), Liverpool, where my current consultant is Professor Toh. My consultant in 1979 when I was first diagnosed with Haemophilia was Dr F E Boulton.
7. I had a thigh bleed on 25 March 1980 and was seen at RLH. The note in my medical records states that my treatment was plan was "*to avoid blood products (Factor VIII too low for DDAVP). Give tubi grip and rest in bed for 3 days.*"
8. I believe Dr Boulton was fully aware of contamination in blood products in 1980 because of the evidence he gave at the Penrose Inquiry (Penrose Final Report; Vol 3; para 21.82).
9. The consultant with overall charge of my treatment after Professor Boulton left RLH in 1982 was B A McVerry who had published a number of papers which relate to viruses contained in pooled blood since 1977.
10. I was first given Factor VIII concentrate on 19 February 1982 as part of a training session.
11. Nobody has ever discussed my Hepatitis B infection with me; it is only through my medical records that I know I tested positive for this. There is a note from the Liverpool Public Health Laboratory dated 27 April 1992 which states "*Hepatitis B infection at some point in the past.*" There is also a reference dated 25 April 1990 which states "*past exposure to Hepatitis B.*"
12. I have never had Factor VIII administered for life saving purposes as I am only a mild haemophiliac.

13. There was a complete failure by RLH to mention any risk factors in relation to the use of blood products. My family and I had no idea that blood products supplied by the NHS could be anything other than sterile and safe. No mention of blood borne viruses was made by RLH until after the media started to break the story of HIV.
14. In fact, the position was exactly the opposite; we were told Factor VIII was safer, less bulky, easier to store and easier to use than Cryoprecipitate. We were also told it could be used for home treatment and taken on our holidays so that it was, overall, a much more convenient way to be treated. Finally, we were told that everyone's treatment was being switched to Factor VIII. I was then invited to 3 different training sessions to ensure that I knew how to inject at home if required.
15. The training sessions were held on: 19 February, 22 February and 1 March 1982. Each session involved the use of one single bottle of Factor VIII even though this, at the time, was considered very expensive therapy. Looking back I do not understand why they didn't just use a cheap saline solution as we were only being trained on how to give an IV injection.
16. I am also concerned that I have since been made aware that my first treatment with Factor VIII took place only 5 weeks after the Oxford Chimpanzee letter was sent to all Haemophilia Centre directors (this was dated 11 January 1982).
17. I have since been made aware of a BPL Factor VIII leaflet from April 1981 which was clearly inserted into my medical records at some stage. This has a section labelled "Warning" and Item 2 clearly states "the risk of transmitting Hepatitis cannot be disregarded". This leaflet is exhibited at **WITN1425002**. This document was never shown to me or my parents.
18. On 11 July 1994 I attended a standard 6 month review at the RLH Haemophilia Centre Clinic. My long term girlfriend was also in attendance with me for the first time as we had intended to discuss the impact of my mild

haemophilia with my consultant to ensure that she was fully aware of the implications regarding injury etc.

19. We were invited in the consulting room as usual. I immediately noticed the unusual set up of the furniture in the room. Two or three tables had been set up to effectively divide the room in half. There were three people sitting behind them. The first was a senior registrar in haematology called Angela McKernan, the second was a haemophilia nurse called Kathy Marsden and the third was a man whose name I didn't notice and cannot recall. He was not someone I had seen before or that I saw again.
20. The consultation began with the registrar asking the standard questions about my general health and if I had had any bleed-related problems. I told them that I was generally well and did not report any problems. The registrar then told me that I had tested positive for Hepatitis C. This took me aback as I had no idea that I was at risk of any infection other than HIV for which I had been tested and informed of my negative status back in 1986.
21. I was also told that the hospital had liver function test (LFT) results which showed that there were issues with my liver for years before my HCV diagnosis. These results were not discussed with me at any stage prior to 1994.
22. I remember feeling stunned. The doctors then gave me what felt like a well prepared spiel about the percentage of people who cleared the virus, the numbers of those who had no symptoms, the availability of "ground breaking" new Interferon treatment and told me that I needed to stop drinking. After a while I asked a question about the health implications for me specifically and how infectious the virus was. I wanted to know whether I could infect my girlfriend and my family. At this point, the gentleman whose name I cannot recall said *"I don't know what you're so worried about, if I got it via a needle stick of something, as I treat a lot of infected people, I'd be out of a job."* He then added *"you've got Hep C but you should count yourself lucky you haven't got HIV."*

23. Following those comments I shut down mentally. I didn't hear anything else that was said during the consultation; I was just desperate to get out and get home.

24. Mr Hay, my consultant at the time, was not present at the consultation. I think it was cowardly that he did not attend and that I was told by someone I had never met before and never saw again. I also believe that I should have been given some warning of what was coming given the magnitude of what I was told at what was supposed to be a standard 6 month review.

25. My girlfriend and I didn't speak for the whole 40 minute drive home. I don't think either of us could comprehend what had happened or what it all meant. When I dropped her home I told her that I would understand if she wanted to end our relationship.

26. I was not provided with any written information following my Hepatitis C diagnosis. I was told to avoid blood to blood contact and that there was a small chance of sexual transmission but no written advice was given.

27. I believe that information should have been provided to me earlier. At least 13 years before my diagnosis manufacturers of Factor VIII were listing Hepatitis as a warning on their products. The information was out there but no one bothered to communicate it.

Section 3. Other Infections

28. I have been warned that I may have been exposed to vCJD. I was first informed of this in February 2001. As there is no treatment for vCJD my family and I tried to put this out of our minds.

Section 4. Consent

29. I was tested for Hepatitis A and B without my consent.

30. I was tested for HTLV-III (HIV) in 1986. I did not consent to this testing.

31. No consent was sought for me to be tested for HCV prior to me being told I had tested positive in July 1994. The hospital had known I was HCV positive since March 1992 and not bothered to tell me.
32. I was never asked to consent to LFTs.
33. I am therefore confident that I was repeatedly tested without my consent.
34. I believe that my doctors obtained patient agreement to change treatment from Cryoprecipitate to Factor VIII concentrate by deceit because they used misleading information and failed to fully disclose the risk associated with Factor VIII.
35. I also confident that I was tested for the purposes of research given that I was first given Factor VIII in a training situation rather than when I required treatment.
36. As a mild haemophiliac who, in 1982, had never been exposed to pooled plasma products I fell within the Centre Directors' description of a "PUP" (Previously Untreated Patient). I don't believe that it was a coincidence that my treatment was changed to pooled factor products just 39 days after the Chimpanzee letter in which the Directors called for a method to *"find out by studies in human beings to what extent the infectivity of the various concentrates has been reduced. The most clear cut way of doing this is by administering those concentrates to patients requiring treatment who have not been exposed to large pool concentrates."*
37. I believe that my consultant could not wait for me to have an actual injury and, instead, abused his position and status by convincing me to use Factor VIII in the guise of a training exercise. I was first treated with Factor VIII for training purposes at a time when I didn't actually need treatment. This was a betrayal and abuse of trust from a consultant and system that was supposed to be patient lead. I believe that we were just the human lab rats in the haemophilia consultants' rush for glory in published research.

Section 5. Impact of the Infection

38. I was informed of my Hepatitis C diagnosis at the age of 25 which means I have spent more than half my life (and virtually all my adult life) with the knowledge of this infection. This has meant that every day, without fail, one of my first thoughts is reliving, questioning, wondering and worrying about how, why and what is going to happen as a result of having been infected. Even though I try not to think about the risk of vCJD this adds to the stress and mental pressure which, in turn, has added to the psychological damage caused by my infections.
39. My Hepatitis C infection has caused me to have a limited concentration span and suffer both mental and physical fatigue.
40. In November 2015 I attended the haematology clinic and advised them of my concerns regarding my liver condition because I had a pressurised sensation in that area. I was advised to return in December for a joint clinic with hepatology. They then carried out a fibro scan and it was my elevated score of 12.1 on this scan which meant I qualified for first line Hepatitis C treatment with Harvoni/Ribavirin.
41. My Hepatitis C was treated with a 12 week course of Harvoni/Ribavirin in 2016 and this "cleared" the virus.
42. When I was given the treatment I was not provided with a patient information sheet regarding the medication and its side effects. I was told by the hepatology staff that there were virtually no side effects. After I started the treatment I found that I was unable to work due to extreme mood swings, aggressive outbursts, lack of patience and generally irritability. All these side effects were noted on the Ribavirin sheet which I was only given a the time of my last treatment. Some of these side effects continue to this day.

43. The physical and psychological effects that my infection has had on me have been devastating. It has affected virtually every decision that my family and I have made for the majority of my life.
44. My girlfriend who attended the appointment at which I was told about my diagnosis went on to become my wife. We have always been concerned about the risk of me infecting her. We both made the decision to try and continue life as normally as possible as we felt that if we dwelled too much on what had happened it would destroy us.
45. After we married we went on to have two children. We felt we had to protect our sons from my diagnosis and we only told them about it when I had treatment with Harvoni in 2016 because we did not feel we could hide 12 weeks of treatment from them. We held off telling them about my diagnosis because we wanted to protect them from suffering the anguish and fears that both me and my wife have had as a result of the stigma associated with Hepatitis C and the potential link with HIV.
46. Only our close friends are aware of my infection. Anyone who found out I was a haemophiliac tended to assume that I was infected with HIV. My close friends have always been very accepting. I informed work colleagues on a need to know basis and was always then quizzed about my HIV status.
47. My diagnosis also had a devastating effect on my parents. They were never able to accept how I was infected with Hepatitis C through the NHS and it was especially cruel on my mother because she fought for 10 years to get me a diagnosis of haemophilia and I was still only a child when I was infected. She blames herself for me being infected and often comments that she was doing the best for me.
48. Generally the day to day issues of living with haemophilia and Hepatitis C has been a nightmare. Before I cleared the virus I worried about every small bleed - for example gums leaving blood on pillows and bedding, on toothbrushes in the sink, small cuts, scratches, nose bleeds - as they all

presented the opportunity to leave spots and smears of contaminated blood around.

49. As I was only 13 when I was infected (and no one informed me) I thought my tiredness and lack of concentration were normal for a teenager. I managed to pass my O-levels and go on to college but I felt unable to concentrate and learn at sufficient pace during my A levels. This, combined with constant fatigue, led to me dropping out of college.

50. I have worked most of my adult life but I feel that in the past I have been overlooked for promotion because of my Hepatitis C. Following my diagnosis my employer felt that they had to consider letting me go because I was an analyst in a food manufacturing plant. Furthering my career seemed pointless. I felt that I needed to emphasise my life/work life balance because I had been told my life could be short. I went from being a well paid senior laboratory analyst to working close to home in administrative roles.

51. Taking lower paid jobs forced my family into an ever increasing mountain of debt and interest. A working life philosophy of "live for the day" also had adverse effects but who wouldn't live like that when presented with my circumstances? I wasn't interested in paying in to savings and pension schemes that either I didn't qualify for or were too costly due to my health conditions. No pension or investment schemes looked a good bet at the time.

52. My wife has been undeniably as stressed, devastated and anxious as me but she has had the extra pressure and demands of helping me when I have been struggling both physically and mentally. Plus, due to financial pressures, my wife has had to work full time even when the children were young to ensure we had a home. We did our best to protect the children for 15 years but this hasn't stopped the shock and upset now they know the truth.

53. My parents had to live with the knowledge that both my brother and I became infected when we were children. I cannot begin to imagine how they must have felt taking us for treatment in good faith that resulted in us becoming infected.

Section 6. Treatment/care/support

54. I have never been offered professional counselling or psychological support. The closest I ever came to it was being invited to speak with other infected haemophiliacs at the hepatology clinic about 3 months after I was informed of my diagnosis. I declined. I don't think assistance in this matter has been inadequate – it was non-existent. I am sure that if I was presented to mental health professionals, a diagnosis of PTSD would be established.

55. I also suffer from survivor guilt. When I meet or hear about haemophiliacs who are HIV positive I immediately think *"thank God I dodged that bullet."* This is not the normal, rational thought of an unaffected person.

56. I was not informed of treatment options for my Hepatitis C until I was seen in the joint clinic at the end of 2015. I believe I should have been kept informed of new developments and the availability of treatments by my treating medical team without me having to approach them regarding the same.

57. I have not been offered regular liver monitoring. The first scans I had were prior to the Harvoni treatment when I complained of feeling pressure in that area. I believe I should still have regular scheduled scans every 6 or 12 months to monitor my liver.

Section 7. Financial Assistance

58. I first heard about the Skipton Fund when it was announced in the national news after its inception in 2004. I also investigated grants from the Caxton Foundation from 2012.

59. In 2004/5 I received the Stage 1 Skipton Fund payment of £20,000. This was a one off lump sum.

60. In 2013 I looked into the Caxton Foundation but was told I was ineligible for financial assistance because it was means tested so I received nothing.
61. In 2015, following a worsening in my condition, and on the advice of both my haematologist and hepatologist, I applied for the Skipton Stage 2 payment because my liver had been classed as cirrhotic.
62. My application was turned down on the basis of insufficient evidence. I appealed and relied on the evidence in my medical notes. I was turned down again and received nothing.
63. In July 2016 I started to receive the new Stage 1 annual payment from the Skipton Fund of £3,500.
64. When the EIBSS was set up I applied for payments under the SCM (Special Category Mechanism) and received £15,655 in 2017/18 and £18,500 in 2018/19. I filled out the application form and sent a supporting letter.
65. The application for the Skipton Fund Stage 2 payment had no clear parameters and you could only take the word of the fund as to whether you were eligible or not. Both my haematologist and hepatologist clearly indicated I should be eligible. I believe the parameters should be published.

Section 8. Other Issues

66. I do not believe it is ethically or morally justified to discriminate between viruses rather than the level of illness incurred and provide pay ex gratia payments at differing levels. If you study the date and amount of the ex gratia payments I have received it is politically and morally embarrassing.
67. I was informed of my infection in 1994 but infected in 1982. For the first 12 years (between infection and diagnosis) I received no financial assistance.

68. From 1994 until the Skipton Fund was set up in 2004 (10 years) I received no payments. In 2004 I received a single ex gratia payment of £20,000.

69. Between 2004 to 2016 I received no payments from any of the Charity status funds.

70. So for a period of 34 years of infection I received an average of £589 a year.

71. Even the new elevated SCM payments which are being offered (on a short term basis) are painfully and embarrassingly inadequate for those diving into the financial abyss as a result of receiving contaminated blood.

Anonymity

72. I do not want to apply for anonymity.

73. I would like to give oral evidence to the Inquiry.

Statement of Truth

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

Signed..... GRO-C ..

Dated: 18/01/2019

MEDICAL SUMMARY

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

- 25.02.1986 HTLV III Neg
- 23.05.1986 Clinic notes record HTLV III Neg
- 14.05.1990 First positive Hep B test – patient not told about it
- 30.03.1992 First positive Hep C test
- 11.07.1994 Letter from Royal Liverpool University Hospital to GP
He is, however, hepatitis C positive and I discussed this with Sean and his partner. I did not want to alarm them unduly about being hepatitis C positive, but I strongly suggested that he reduces his drinking as much as possible. We will check his liver function tests and then decide how to take this further on the basis of those. He is HIV negative, he would be a candidate for Interferon.
- 10.10.1994 Letter from Royal Liverpool University Hospital to GP.
...we discussed hepatitis C and interferon at length. His liver function tests are persistently mildly abnormal but his immunoglobulins are completely normal, which suggests that he probably has chronic persistent hepatitis.....We discussed Interferon. There seems no immediate urgency about this, and with a 25% long term response rate he is also not very enthusiastic about this prospect, although it will have to be kept under review. I have advised him to moderate his alcohol intake. Until he heard about hepatitis C he was drinking 6 or 7 pints on Friday, Saturday and Sunday. He has now cut back to 6 pints. I have advised him that from the point of view of his liver it would be better if he spread his 6 pints out over the week.
- 11.04.1995 Hepatitis C PCR Positive
- 16.10.1995 Clinic notes. Sean is finding he is having conflicting information/advice. Very angry he hadn't heard he was HCV +ve earlier for many reasons.
- 27.11.1995 Letter from Prof Toh to GP.
We talked at length about hepatitis C and his anger/frustration with this. At the present time, he is uncertain about Interferon, although I have

tried to encourage him on the basis that the side effects can be controlled to some degree. It would also be the only way to clear the virus, and our successes have generally been in patients of Sean's age. As he was still very uncertain by the need of the clinic, I offered for him to meet up with other haemophiliacs of similar ages who have tried Interferon.

- 28.07.1997 Clinic notes. LFTs stable.
- 07.02.2001 Possible vCJD letter
- 13.08.2003 Clinic notes. Hep C in 1997 AB +, PCR +. Minimal alcohol now. Wife wishes to be tested. Updated re Hep C + Rx (+ ex gratia payment). Wife consents to Hep C screening and results over the phone. HCV AB –
- 07.04.2016 Letter from Royal Liverpool to GP
He has completed treatment today. Sean informs me that he continues to be tired and a little bit snappy.
- 16.05.2016 Letter from Dr Lindsay to GP
He has completed his anti viral treatment and his Hepatitis C viral load is now undetectable.
- 07.07.2016 Letter from Royal Liverpool to GP.
He is now 3 months post treatment with Harvoni and Ribavirin. I was delighted to tell him he remains Hep C PCR negative and has therefore cleared the virus.
- 15.08.2016 Letter from Dr Loizou to GP.
Transfusion transmitted infection (hepatitis C). Following treatment for hepatitis C has developed numbness in both hands and all his fingers.
- 27.04.2017 Letter from Royal Liverpool to GP.
He is now 12 months post Hepatitis C treatment. He was negative at 3 and 6 months post treatment.....fibroscan was normal at 8.8 Kpa and his LFTs are entirely normal.