

Witness Name: Eleanor Lynne Nevin

Statement No: WITN2786001

Exhibits: 0

Dated: June 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ELEANOR LYNNE NEVIN

I, Eleanor Lynne Nevin will say as follows:-

Section 1. Introduction

1. My name is Eleanor Lynne Nevin. I was born on GRO-C 1973 and I live at GRO-C GRO-C Merseyside, GRO-C with my husband, Sean Philip Nevin, and our two sons.
2. Sean (born on GRO-C 1969) was infected with Hepatitis B and Hepatitis C (genotype 1A) from contaminated blood products.
3. Sean has provided his own Witness Statement to the Inquiry (WITN1425001). Our sons, George (aged 19) and Harvey (aged 17) have also provided Witness Statements to the Inquiry (WITN2787001 and WITN2788001 respectively). Sean's brother, Andrew, was similarly infected with Hepatitis C as a result of treatment with contaminated Factor VIII concentrate and has given a Witness Statement to the Inquiry (WITN2785001).

4. This witness statement has been prepared without the benefit of access to Sean's full medical records. If and in so far as Sean has been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

5. Sean was diagnosed with mild haemophilia A (clotting factor 5%) when he was 10 years old.
6. Sean has always been treated at the Roald Dahl Centre at the Royal Liverpool Hospital (RLH), Liverpool. He was under the care of Professor F E Boulton from 1979 when he was first diagnosed with haemophilia. He is now under the care of Dr Toh.
7. Sean had a thigh bleed on 25th March 1980 and was seen at RLH. The note in his medical records states that his treatment was "*to avoid blood products (Factor VIII too low for DDAVP). Give tubi grip and rest in bed for 3 days.*"
8. Sean and 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. Professor Boulton left RLH in 1982 and Sean came under the care of Dr B A McVerry who had published a number of papers which relate to viruses contained in pooled blood since 1977.
10. Sean was first given Factor VIII concentrate on 19th February 1982 and then on 22nd February and 1st March 1982 as "training" in how to self inject at home if required. He was not injured. Factor VIII was considered to be very expensive therapy at that time and its use as a training exercise was completely

unnecessary. Sean has never needed Factor VIII administered for life saving purposes as he is only a mild haemophiliac.

11. The Factor VIII training/treatment took place just 5 weeks after the Oxford Chimpanzee letter was sent to all Haemophilia Centre directors (this was dated 11th January 1982).
12. Sean and his family were not warned of any risk prior to being given Factor VIII concentrate. The "Warning" contained in the BPL Factor VIII leaflet inserted into Sean's medical records (exhibited to Sean's Statement) that "the risk of transmitting Hepatitis cannot be disregarded" was never shown to Sean or his parents.
13. Sean's mother has been particularly adversely affected, blaming herself for (unknowingly) allowing her two sons to become infected. She is now in failing health and is burdened with guilt when she in fact thought that she was doing the right thing by her sons at that time. Sean's father (whilst alive) would never so much as speak of the matter, preferring to live in a state of denial.
14. I met Sean when I was 17 years old and we formed a relationship in April 1992. On 11th July 1994, I accompanied Sean to a routine 6 month appointment at the RLH Haemophilia Centre Clinic. We were not officially engaged but had discussed marriage. Sean wanted me to hear more from his consultant (Dr Hay at the time) about his treatment in order to ensure I was fully aware of the implications regarding injury etc. We also wanted to talk haemophilia and about the implications of us having children. The last thing I expected was to hear that Sean had Hepatitis C in the manner we both learned of it on that day.
15. Dr Hay was absent at the appointment even though Sean expected to see him. The room was effectively divided in half by three medical professionals sitting behind two or three tables. The first of the three professionals was a senior registrar in haematology called GRO-D the second was a haemophilia

nurse called GRO-D and the third was a man Sean did not know and has not seen since.

16. The registrar asked Sean some preliminary questions about his health. The third man, unknown to us, then interjected and informed Sean that there were references in his medical notes to him having Non-A Non-B Hepatitis recently given a name, Hepatitis C (HCV). He was blasé about the matter and arrogant and flippant in his attitude. At one stage he laughed, put his hands behind his head and said “for all I know I could have it, dealing with you all and I would then be out of a job. You should count yourself lucky that you do not have HIV”.
17. Sean was completely caught off guard. The way in which he was told was disgraceful. Sean was in his mid twenties sat with his girlfriend in her early twenties. There was no compassion. The Centre seemed to have drafted in someone who Sean had never seen before and would never see again to break the news. They were clearly primed to impart a massive piece of news to Sean and ready to deflect any resulting criticism.
18. Sean was also told that the hospital had liver function test (LFT) results which showed that there were issues with his liver for years before his HCV diagnosis. Sean was not informed of this prior to 1994.
19. We were told nothing about potential routes of transmission of the virus at the meeting. This was information that we had to get for ourselves afterwards. At a later meeting we were told that there is a minimal chance of transmission through sexual relations. Sean was also later told that he could develop cirrhosis and liver cancer within 25 years of diagnosis. He was not told of the diagnosis for the first 12 years of being infected.
20. Sean and I didn't speak for the whole 40 minute drive home from that initial meeting. Sean said he would understand if I wanted to end our relationship. I

don't think either of us could comprehend what had happened or what it all meant.

Section 3. Other Infections

21. Sean and I had no idea that he was infected with Hepatitis B until he recently saw the reference to a positive test result and past exposure to the virus in his medical records. We have been unable to get any further information about this and they shut us down at the hospital anytime we raise it.

22. Sean was sent a letter telling him that he may have been exposed to vCJD and was later given the option as to whether he wanted to know. We decided not to find out and have tried to put it out of our minds. We have however since been made aware that Sean was indeed exposed to a problematic batch.

23. Sean was relatively recently scheduled for an endoscopy that was cancelled on the day because Sean had not arranged his own Factor VIII cover. We were not aware it was Sean's responsibility to do so instead of the hospital's. When it was rescheduled, they were going to again cancel because of the vCJD risk. The endoscopy went ahead but Sean was made to wait to the very end of the day in order to be the very last patient undergoing a procedure.

Section 4. Consent

24. Sean was tested for Hepatitis A and B without consent.

25. Sean was tested for HTLV-III (HIV) in 1986. He did not consent to this testing.

26. Sean and I believe that he was repeatedly tested without his consent.

27. I believe Sean to have been used as a guinea pig for research purposes in 1982 and throughout. Sean was not injured and did not need Factor VIII concentrate.

He was given misleading information and failed to fully disclose the risk associated with Factor VIII. He was made to believe he was being given a wonder drug whereas in reality they just wanted to test him.

Section 5. Impact of the Infection

28. Sean has a lot of important documents missing from his medical records but it is noted that Sean was tested positive for Hepatitis C before we started going out together in April 1992. Sean was very ill with an undiagnosed condition and was hospitalised within three to four weeks from the start of our relationship. He had blood in his urine and couldn't eat. That same summer, Sean went away on a family holiday to Tenerife. He was again very unwell with stomach pains and his mother told me that she was really worried that that holiday would be Sean's last. He was thin as a rake and very weak on his return.

29. I was a student when Sean was informed that he had Hepatitis C through contaminated blood. I started to write to various MPs (and got my friends to do the same). My mother wrote to John Major. We struggled to get answers, Kenneth Clarke being the most dismissive. Sean and I came across the Manor House Group and went to about four meetings before we realised that it was not good for our mental health. At each meeting we heard that someone had died or had become seriously ill. We had to look to the future for and it was a sad and constant reminder of the expected outcome for Sean.

30. We have worried about our boys becoming infected and have had to tell them not to go near their father's razors or toothbrush, keeping them separate to everyone else's. I have gone mad with bleach clearing up Sean's blood if he has an outward bleed like a nose bleed. We have not until relatively recently told the boys as we have not wanted them to be burdened with the worry that Sean and I share.

31. The mental strain of wondering and worrying about how, why and what is going to happen as a result of Sean being infected is immeasurable. I was tested for HCV after the children were born but I haven't been tested since (by choice). Every time Sean had a cold or flu I have been worried sick. Sean became very upset and distressed 6 or 7 years ago when he was experiencing niggling pain in the stomach. He was convinced that he would never see his boys grow up.
32. In 2015 Sean attended the haematology clinic and advised them of his concerns regarding his liver condition because of a pressurised sensation in that area. He was then invited to attend a joint clinic with hepatology. A subsequent fibro scan revealed an elevated score of 12.1 which meant he qualified for first line Hepatitis C treatment with Harvoni/Ribavirin.
33. Sean was treated with a 12 week course of Harvoni/Ribavirin in 2016 and this "cleared" the virus. An undetectable viral load is evidence that the virus is suppressed and not necessarily permanently cured. It was only when Sean was about to embark on the treatment that we told our sons about Sean having HCV.
34. Notwithstanding his hepatology referral, Sean has never had contact with his Hepatology Consultant. All Sean's appointments have been with the Nurse consultant, Helen Caldwell. We were both told by Ms Caldwell that Sean would not experience any clearing treatment side effects (or virtually none) and that was confirmed through an informal conversation I had with one of the nurses. The tablets were given to us without the box and without a patient information sheet regarding the medication and its side effects. The patient information sheet was only provided at the time of Sean's very last treatment.
35. The cost of the treatment seemed to be Ms Caldwell's paramount concern. She made it clear that there was a limited budget and that unless Sean accepted the offer of treatment straight away, he would miss out. Sean accepted.

36. The physical side effects of the treatment for Sean were horrendous. Sean was grey in colour. He had rashes, flu like symptoms, nausea and suffered with insomnia. His skin was dry and flaky. He gained weight and experienced tingling in his hands.
37. The mental effects of the treatment on Sean were equally horrendous. Sean would fly off the handle, with extreme irritability and wild mood swings. We always sat down together as a family for our tea whatever went on with us. At the time of Sean's treatment I lost count of the times, things would fly off the table and Sean would storm off. He had no motivation for anything. His one saving grace was our young husky that needed walking. Sean would take her out to walk on the beach but that was all he would do. Life was hell for him.
38. During the treatment period Sean developed anemia and when Sean discussed the matter with Ms Caldwell, she said that she may have to halt the treatment. Sean has not been the same since the treatment.
39. Sean suffers with chronic fatigue. Until the treatment he worked throughout his adult life but it has been a struggle for him. HCV has adversely limited the work that Sean can do. When I met Sean he had a promising career working as an Analytical Chemist in a food manufacturing plant. Disclosure to prospective employers of being infected with HCV has been prohibitive for Sean and he has instead found office based employment through people he knows. Sean is exhausted just working Monday to Friday from 9 to 5. He would often fall asleep in the early evening mid conversation. One particular job nearly destroyed us. He was under so much pressure at work it affected his mood. He was working away in St Helens and was often contacted by his team for help at weekends. He was exhausted.

40. Sean is what I would describe as a 'man's man' and does not give in easily. Sean has always wanted to provide for his family. He is a proud man. At one stage he was trying to sit A levels at night school whilst working. We have struggled financially all our working lives and have ended up in debt and mortgaged to the hilt. We took out a second mortgage in an attempt to consolidate our debt which has proved a killer for us. I work as a teacher and my salary merely covers our bills. We had to survive throughout two maternity leaves and we borrowed our friends' car for three years because we could not afford one of our own. Our finances are in a mess through no fault of our own. Life has been hard and stressful, worrying about Sean's health, our lack of finances and the welfare of our sons.

Section 6. Treatment/care/support

41. Sean was offered Interferon treatment in 2004. Aside from what we had heard about the horrendous side effects of that particular treatment as well as it's poor success rate, Sean and I were at that time wholly reliant on his salary. Our boys were very young at that time and it just wasn't an option for us. We would have lost everything if Sean had been unable to work. Aside from that, no treatment was offered and/or discussed until 2016.

42. Sean would have people question him about his drinking habits (particularly Professor Hay), warning him of the risk of liver damage and ignoring the fact it is HCV damaging his liver. He was not properly monitored and was discharged from the liver unit after clearing his treatment. He had to complain about the discharge (which we were later told was a mistake) and insist upon an annual scan.

43. I have never been offered professional counselling or psychological support and nor has anyone in the family.

Section 7. Financial Assistance

44. Sean only heard about the Skipton Fund through the national news and received an ex gratia payment in 2004/5. In 2015, following a worsening in Sean's condition, and on the advice of both Sean's haematologist and hepatologist, he applied for the Skipton Stage 2 payment because his liver had been classed as cirrhotic. Because Sean is now unable to work and in order to get by, we borrowed money from Sean's parents, promising to repay the money when the Stage 2 payment came through.

45. Sean's application to the Skipton Fund was subsequently turned down and his appeal refused and he received nothing. The decision destroyed Sean. His liver was poor enough to meet the NICE criteria for clearing treatment but, apparently, not for the Stage 2 payment.

46. In July 2016 Sean started to receive the new Stage 1 annual payment from the Skipton Fund of £3,500. When the EIBSS was set up he applied for payments under the SCM (Special Category Mechanism) and received £15,655 in 2017/18 and £18,500 in 2018/19.

47. Sean has been infected since 1982. Between 2004 (when he received the Stage 1 ex gratia payment) and 2016 he received no payments from any of the Charity status funds. So for a period of 34 years of infection he received an average of £589 a year.

Section 8. Other Issues

48. Sean and 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. It is also very wrong that the payments are means tested. I am one of many being penalised for bringing in a full time income.

49. 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

50. I do not want to apply for anonymity.

51. 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 06.06.2019

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 end 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.