Witness Name: P J Lewin
Statement No: WITN0849001
Exhibits: WITN0849002-10
Dated: July 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PETER JOHN LEWIN

I, Peter John Lewin, will say as follows:-

Section 1. Introduction

1. My name is Peter John Lewin of GRO-C Dorset, GRO-C My date of birth is GRO-C 1952. I live with my wife Penny Lewin and we do not have any children. I have not worked since my late 40s due to ill health.

2. **This statement has been prepared without the benefit of access to my full medical records; some are missing and some are illegible.**

Section 2. How Infected

3. I have moderate Haemophilia A.

4. I initially received blood transfusions as a child and then cryoprecipitate from 1971.

5. I was first treated with Factor VIII concentrates in 1977; my first use was to cover an emergency operation on a ruptured umbilical cyst. I believe that this could have been experimental use as I was closely monitored by a researcher whilst I was an inpatient for this operation.

6. My initial care as a child was at Northampton General Hospital, with occasional input from John Radcliffe Hospital in Oxford. However, I was only given blood transfusions at these hospitals and no cryoprecipitate or Factor VIII concentrates.

7. We then moved to London in 1970 and I attended St George's Hospital, in Tooting, for treatment on an "*as and when required basis*". I was treated with cryoprecipitate until 1977.

8. My family then moved to GRO-C in the GRO-C and I was treated on an "*as and when required basis*" at Boscombe Hospital and the Royal Bournemouth Hospital; where I continue to be treated today. I underwent surgery at both of these hospitals.

9. I have also had surgery at the Hampshire Comprehensive Care Centre in Basingstoke and at Queen Alexandra Hospital in Portsmouth.

10. Aside from my operations, I was only receiving Factor VIII on an "*as and when required basis*" for injuries. The Factor VIII was initially administered at the hospital although I progressed to home treatment in or around 1988/1989. Prophylactic treatment was not started until 2005.

11. My consultants were Dr Oscier, Dr Green (Boscombe), Dr Alison Worsley (Royal Bournemouth) and Dr Mainwaring (Bournemouth).

12. I obtained my UKHCDO records in 2004 which show a number of batches that were "*different*" from the normal BPL Factor VIII batches. These "*different*" batches may have been the contaminated batches. Copies of these records are attached as **Exhibit WITN0849002.** I have marked three of the records as "*different*" and I gave them what look like batch numbers. I do not know where I obtained these codes; they may have been identified in the press or by the Haemophilia Society as known infected batches.

13. I was infected with both Hepatitis B and Hepatitis C from blood/blood products. Looking back through blood test results shows that I had no Hepatitis B antigens in February 1985 so I was not infected with Hepatitis B until after this date.

14. I was never given any information or advice regarding the risks of infection from blood transfusions, cryoprecipitate or Factor VIII concentrates until after I was advised about my HCV (Hepatitis C) status in June 1994. If the risks had been spelt out I would certainly have avoided surgery for no life threatening conditions. I would not have had a vasectomy in 1981 if I had known about the risks regarding Factor VIII.

15. My Hepatitis C status was revealed to me, during a consultation with Dr Worsley, on 8th June 1994. I only found out that I had contracted this virus because I specifically asked to be tested for this at the consultation with Dr Worsley.

16. It transpired that I had already been tested for the virus, without my knowledge or consent, via a stored blood sample. **Exhibit WITN0849003** is an extract from my medical records entitled "*Annual Review Sheet*" which states "*Hep C store-pos*". I do not know when the stored blood was tested but I do know that a blood test result dated 21st February 1985 contained a Hepatitis Risk sticker on it and I attach this as **Exhibit WITN0849004**.

17. I do not remember receiving much, if any, advice in relation to Hepatitis C and certainly no offer of counselling. My wife was offered a test for Hepatitis C during the consultation of 8th June 1994 which is evidenced by **Exhibit WITN0849005**; a review sheet dated 8th June 1994 which states "*Testing of wife offered*". This exhibit also confirms that I was told about the existence of the Haemophilia Society.

18. I obtained most information pertaining to Hepatitis C from The Haemophilia Society Meetings and their publications. I also recall travelling to a meeting in Coventry which was run by the Haemophilia Society to find out more information, which was after the first attempts of my Hepatitis C treatment failed, in or around 1996.

19. Following my consultation with Dr Worsley on 8th June 1994, I was referred to Professor Arthur at Southampton Hospital to discuss the management of my Hepatitis C. I recall seeing him on 16th October 1995. Subsequent to this appointment, he recommended treatment of my Hepatitis C with Interferon which began on 17th January 1996. The first round of this treatment lasted for 3 months and was not effective so my dose was doubled for the following 3 months. The doubling of the dose meant that I was receiving 5 million units thrice weekly. During this time my viral load doubled and unfortunately the treatment was unsuccessful. In fact, it was not until 2016, following treatment with Harvoni (Ledipasvir 90mg and Sofosbuvir 400mg) and Ribavirin (600mg), that my Hepatitis C became undetectable in blood samples.

20. My Hepatitis B status was revealed to me in May 1990 when I was informed that I had antibodies to Hepatitis B thus confirming that I must have been previously infected with, but now cleared, of this virus. I only found out about Hepatitis B following my request to see whether I should be vaccinated against this. **Exhibit WITN0849003** dated 16th May 1990 confirms "*Letter to GP re hep B vaccination*". **Exhibit WITN0849006** is a letter dated 23rd

May 1990 from Dr Worsley to my GP, Dr Thomas which states "*he had detectable anti hepatitis B antibodies consistent with previous infection*". **Exhibit WITN0849007** is a letter, also dated 23rd May 1990, from Dr Worsley too me which states "*there were significant antibodies to hepatitis B showing that you must have had a previous infection with this and that you are now suitably immune and do not need vaccination*".

Section 3. Other Infections

21. I recall that in or around 1994 Dr Worsley advised me that I had been put at risk of vCJD. However, she said the risk was minor but that it was not possible to test for the presence of vCJD until death.

Section 4. Consent

22. I believe that I was tested for various viruses without my knowledge and consent. **Exhibit WITN0849006** states "*he was HIV negative in 1988*". I was not aware that I was being tested for HIV and I was not provided with any test results in this regard. I have also noted from looking at my medical records that I was being tested for antibodies to HTLVIII on an annual basis.

23. Rather worryingly I was not given the results of tests at, or even close to, the time the tests were carried out.

24. The only time I believe that I may have been subject to research was in 1977, as previously stated, when I had an operation at St George's Hospital and received Factor VIII concentrate for the first time. During this time I was under daily observation and supervision by a research assistant.

Section 5. Impact

25. Finding out that I was Hepatitis C positive came as an enormous shock. I was very surprised that it had taken medical professionals so long to share the news of my infection with me; given that they had known for so long.

26. This delay put my wife at an enormous risk of becoming infected with Hepatitis C because I had absolutely no idea that I was infected. Furthermore, I was a teacher and the presence of this virus could have seriously affected my future career path.

27. **Exhibit WITN0849006** suggests that they were already testing me for Hepatitis C (Non-A Non-B Hepatitis [NANB] Hepatitis as it was known then) as early as 1985 but not informing me about the testing or the results. This letter was sent to my GP, Dr Thomas, from Dr Worsley but not copied to me. There was absolutely no excuse not to copy this letter to me because **Exhibit WITN0849007** was written to me on the same day by the same consultant. The letter to me also fails to include the fact that I had been tested for HIV in 1988. **Exhibit WITN0849008** is an extract from the Observer Newspaper of 7th November 1999. I refer in particular to the paragraph which starts with "*An article written by doctors in the Lancet in 1975….*", which shows that testing for NANB Hepatitis/Hepatitis C was taking place in 1974 at the Bournemouth Haemophilia Centre with half of the patients being found to be infected. It would seem safe to presume that this testing continued from that date and I would have been tested (without my knowledge) on moving to that treatment centre in 1977/1978.

28. **Exhibit WITN0849009** is part of a letter dated 23rd May 2001 which confirms that some of my medical notes are missing.

29. Turning to the mental effects of my infections, I believe that I have dealt with what has happened to me in the best way that I was possibly able to. I think I handled things admirably but it did take me a long time to both reconcile and come to terms with the fact that I had to give up work due to the debilitating effects of Hepatitis C. However, a change to a safer Factor VIII concentrate, when it became available, would have led to a more settled mind and better mental health. Indeed I had First Replenate in 1996 but then 8Y again. I then had Replenate and Alphanate up until 2002.

30. I have suffered physically because my body is weak as a result of the chronic fatigue and arthritis. The Hepatitis C has caused the chronic fatigue and also a weakened immune system meaning that operations to lessen the pain of arthritic joints have been less than successful due to infections and the poor healing of joints that were being fused.

31. I have Cirrhosis, Angina and Atrial Fibrillation; my stent was fitted in 2018.

32. I have had operations on both ankles and these have had complications necessitating further surgery. My left ankle became severely infected and the metal work had to be removed. The bones did not fuse and I am now left with minimal movement and associated pain.

33. My right ankle would not bond/fuse after the initial operation which was carried out in Basingstoke Hospital and I was therefore referred to another specialist team at Portsmouth Hospital. Two surgeons re-opened my right ankle, prepared new bone surfaces and then fitted an external fixator to compress the bones to ensure that a proper bond/fusion took place.

34. I suffered a great deal when I commenced the Interferon Treatment in 1996. This treatment caused me to develop severe depression as well as debilitating joint and muscle pain which impacted heavily on my lifestyle and my wife, who was holding down a full time job whilst also caring for me. This was a very strained and difficult six month period of our lives.

35. Following this unsuccessful treatment I had to wait until 2016 to embark upon the Harvoni Treatment. I did not suffer such severe side effects on this treatment and following conclusion of this treatment, Hepatitis C was no longer detectable in my blood tests. However, I am still tested for Hepatitis C every 6 months and my Cirrhosis is monitored for any signs of progression to liver Cancer. The virus may be undetectable but the ramifications of my infection continue to the present day.

36. My home life was not too badly affected by my infections except during the Interferon treatment cycles and also by the constant lack of energy which I would describe as chronic fatigue.

37. I was heavily involved in Disabled and Paralympic Sailing and ended up as a member of the shore crew for another heavily disabled sailor who was campaigning for the Paralympics. He asked me to accompany him to one of the Disabled World Sailing Events in the US. However, I had to turn this invitation down due to US officialdom at the time because Hepatitis C was a notifiable disease in the US and normal visa arrangements were not applicable. In order to enter the Country I would have had to attend the American Embassy for an interview, that I would have had to pay for, and even then I may not have been able to obtain the requisite special visa to allow me to enter the US.

38. I was lucky that neither my wife nor I suffered much stigma. Socially I have been very open with my friends and others about my Hepatitis C. Those in whom we confided were extremely supportive and accepting of my condition. However, I was not working or looking for work for some of the time when I was infected so I did not have to deal with any possible prejudice or difficulties in this regard. However, I would have been unable to return to teaching if I had still been able to work as had been my previous "*fall back*" intention.

39. I had to give up work due to Haemophilic Arthropathy and Hepatitis C. Without the addition of the Hepatitis C, I may well have been able to return to work, however, I have been on disability benefit from the age of 42 and unable to work due to ill health.

40. It was therefore a struggle financially until the Skipton Trust payment was received 10 years later because we were reliant on a small private pension and disability benefit.

41. My wife now works part time so that we can spend more time together. This was initiated by the Hepatitis C information that my condition was, and still could be, life shortening. I am very worried that if I should die my wife will be left with a considerably reduced income and hence a poor standard of living. Currently, my disability benefit has been replaced by the Personal Independence Payment (2017 until 2021) and I also have a state pension.

42. My wife has been very much affected by having to support me through the treatment and she has also had to adapt to my much less active lifestyle. GRO-C GRO-C

43. I think one of the biggest impacts of what has happened to me was the fact that the consultants did not tell me about my Hepatitis C status when they became aware; this delay hugely affected my life because I commenced setting up my own business which carried with it its own innate risks but it was in fact the Hepatitis C which caused me to have to fold this business only 4 years after I set it up. This was very upsetting and brought with it huge financial implications.

44. Had I been made aware of my Hepatitis C status I would never have embarked upon setting up my own business. My decision making would have been very different had I been furnished with the true facts about my health. As a result of starting my own business my wife and I had to move house in approximately 1993 to a property that was able to accommodate a workshop. I also transferred my teaching pension to a private one.

Indeed, the private pension was also mis-sold to me, thus compounding the problem. The private pensions then suffered their own plight; further adding to our financial difficulties.

45. Ironically had I remained in teaching, in all likelihood, the school would not have wanted to continue to employ me with Hepatitis C and I would therefore have had to leave teaching on medical grounds and no doubt with a far healthier income pot than I have now.

46. My decline in health (I was unable to manage stairs) was so rapid that we had to move house, to downsize, again in 1994/1995. This was upsetting and had further financial implications, as we had only moved one year prior to this, in order to obtain further space for the business.

Section 6. Treatment/Care/Support

47. Support has been in short supply and had to be sought rather than it being offered. Treatment was as good as what was available at the time but not always with the best products.

48. Following my infection with Hepatitis C I had to go to a specialist hospital dentist because my normal dentist was reluctant to treat me.

49. Counselling and psychological support has never been suggested or offered, either at the time of, or after, the initial diagnosis. Rather it was expected that I was supposed to just carry on as normal.

50. As stated previously, GRO-C However, it was not offered and had to be both sought and fought for.

Section 7. Financial Assistance

51. I found out about the Skipton Fund through the Haemophilia Society in early 2004. I received the Stage 1 Payment in October 2004 and the Stage 2 Payment in 2015. I also received monthly payments.

52. I also received recent top up payments from the EIBSS and assistance with travel costs when hospitalised.

53. In general, I found that that the process of applying for support from both the Skipton Fund and the EIBSS was lengthy and involved repetitive form filing.

54. The application procedure for the top up payments involved rather intrusive means testing.

55. With the recent increases, the top up payments have brought about a reasonable standard of living. However, I am still fearful for my wife's predicament in the event that I predecease her.

56. It also concerns me that some recipients of the top up payments have been subject to investigations by HMRC and hence we are advised to have these payments made to an account which has been specifically set up for the sole purpose of receiving these payments. This almost makes the system and the payments appear covert.

Section 8. Other Issues

57. When the campaigning gained momentum in 1995, and in the subsequent years, I wrote several letters to the Department of Health, the Prime Minster and to others and I retained the replies. The replies seemed to pass the buck down to local clinician level because they stated that that was where the decisions were made with regard to the use of Factor VIII. The replies did admit that recombinant Factor VIII was safer but did not endorse its sole use. The replies also referred to the financial implications of the decision making process which is supported by **Exhibit WITN0849010**.

58. I want this Inquiry to clarify what happened and why it happened. I think that the way in which some of the payments have been made is problematic. If I die tomorrow, my wife will only receive one small payment from the EIBSS. Whereas if I had been properly provided for with a suitable and sufficient compensation package, I could be confident that my wife would be provided for.

Anonymity, disclosure and redaction

59. I do not wish to apply for anonymity and I would be willing to provide oral evidence to the Inquiry if selected.

Statement of Truth

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

Signed...... GRO-C ....

Dated......19-7-2019...........