

Witness Name: Mr Terence O'Hora

Statement No: WITN1438001

Exhibits:0

Dated: November 2018

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF TERENCE O'HORA

I, Terence O'Hora will say as follows:-

Section 1. Introduction

1. My name is Terence O'Hora. My date of birth is GRO-C 1955 and I live at GRO-C
 GRO-C. I am currently renting a room at the above property. I am a self-employed skilled.
2. I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15 October 2018.
3. I came to the United Kingdom from Belfast in 1977.
4. I was diagnosed with mild Haemophilia B (also know as Christmas Disease) during surgery after a nose bleed in or about around 1972/1973. GRO-C

GRO-C
5. 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

6. On 27 November 1977 I had a very serious nosebleed and was initially taken to Bury St Edmunds and treated with Factor IX (FIX) (I do not know the batch number). I was told by the doctors the factor that I was given at Bury St Edmunds did not help stop the bleeding. I was then transferred to Addenbrooke's Hospital and was told that I nearly died. The doctors could not stop the bleeding so gave me a lot of blood (approximately 39 units, as per my medical records) and gave me a lot of FIX (approximately 41 bottles, 22,960 units, as stated in my medical records, dated 15.12.1977). I was told that my neck was cut open and they had to tie my carotid nerve. I was discharged on the 12 December 1977.
7. Between 1977 to around 1979 I would only visit the hospital now and again for example follow up appointments and dental treatments.
8. In January 1980, Dr Chalmers was making inquiries about me and my brothers stating that he has not seen me for 2 years and if I could make contact with him. This came to light when I reviewed the medical records.
9. There are notes in my hospital records from the Haematology Centre, Addenbrooke's Hospital (HCAH) dated 10 October 1984 from Dr Seaman, Consultant Haematologist which states "I think it possible therefore that he could have his tooth extraction under Cyklokpron cover without any specific FIX therapy. I do not think we would wish to give him any blood product unless we absolutely have too..... we need only to resort to FIX therapy if you get into any serious trouble". I believe this is very strange as I always received factor for all my dental treatment where a tooth is being removed. I believe that Dr Siemen is saying this because he had knowledge of the risk of being infected by HIV.

10. There is a letter in my medical records from the HCAH, dated 20 February 1985 from Dr Seaman addressed to me stating '....I hope you will be able to attend the laboratory in order to have some blood taken for routine test as I stated in my letter of January 1985'. I confirm that I did not receive any form of communication from the hospital in January 1985 and the letter, dated 20 February 1985 is the first letter that I received from the hospital.
11. I attended hospital a few days later (25 February 1985) to have routine blood tests. At the time I did not think anything of it as I thought the routine blood tests were done because of my Haemophilia. No one had told me that I was being tested for Hepatitis B (Hep B) and HIV. I now know that I was tested for Hep B and HIV because the medical records show that blood was taken on the 25 February 1985, which is when I attended hospital for the routine blood tests. The results for the blood tests were reported early March 1985 and late April 1985. The tests confirmed that Hep B was found and HTLV was not found. I was not told about the results.
12. I received a letter from Dr Seaman, dated 12 March 1986 which states that 'it is now approximately a year since we tested your blood to see whether you had been exposed to AIDS virus, and you will remember that the test on that occasion was negative'. I was shocked to receive this letter. As previously stated I was never told that I was being tested for HIV/AIDS. This was the first time that I was told that I was tested for AIDS. I thought to myself 'do I have to be tested for AIDS every year even if I did not receive any Factor'. I had further blood tests on the 21 March 1986. I was informed by way of letter from Dr Seaman, dated 24 April 1986 that 'your blood is still negative for antibody to the AIDS virus'.
13. I note from my medical records (letters dated, 25 February 1987, 20 July 1988, 16 August 1989 and 23 August 1989) that Dr Seaman was trying to find out where I was living by writing to my GP in Norfolk. It seems that they were very interested in my life telling my GP that I should be tested now and again, but not stating why, even though I had no need to get in touch with them. I had no knowledge of this until I reviewed my limited medical records. When they found me, I was asked to have more blood tests, which I did. They only

tested for HIV. The result for HIV was negative. I am sure they also tested me for Hep B and C but there is no record of this.

14. In or about 1988, I hit my knee between two cars. In my medical records there is a letter from Dr Baglin to Dr Graeme, dated 14.06.1994 stating that I required FIX replacement on two occasions in the past, 1977 for a severe epistaxis which required ligation of external carotid artery and 1988 following a car accident. I confirm that I was not in a car accident but I hit my knee between two cars. I did attend hospital as a result and I was given FIX.
15. In or about January 1990, I had an incident where I passed blood. I attended HCAH. The bleeding had stopped spontaneously when I got to the hospital. The doctor at the hospital gave me 2 bottles of FIX. This was the third time that I was given FIX.
16. I received a letter from Dr Baglin, dated 6 April 1991 stating that they had not seen me since January 1990.... "My records indicate that you received some FIX concentrate at this time and I wonder therefore if I could review you to make sure that all is well". I found this letter to be strange as they were asking if I was okay after receiving FIX. I was not told the reason why they were asking 'if all is well' after having FIX concentrate and I did not ask.
17. In May 1991 I had further routine blood tests. I was not told what they were testing. Again I thought it was because I was a Haemophilic. They tested me for Hepatitis B (Hep B), Liver function tests, HIV, and Hep C without my knowledge. I was not told what the results were. However, there is a letter from Dr Baglin, HCAH to my GP, dated 31 May 1991 confirming that 'investigations revealed evidence of past Hep B and Hep C infection'. I did not receive any form of communication from the hospital or my GP about my results.
18. In May 1992, my medical records show that I had a liver function test. Again this was done without my knowledge.
19. In October 1992 I went to my GP and requested a medical check form for my then employers. I informed my GP that I had HIV tests annually at HCAH as

part of my normal blood tests for my haemophilia. My GP states in his letter (which I had no knowledge) that "He tells me that he has had an HIV test annually as part of his normal test for his Christmas Disease. I could not find no results of this although I note he is Hep B and C positive". I had no knowledge that I was Hep B and Hep C positive at this point.

20. On the 21 May 1993, I attended the clinic for a normal routine check and saw Dr Richards. He sat me down to have a chat about me generally. This was the first time that I was told that my blood tests showed that I was Hep C positive. The doctor reassured me that although the overall prognosis was unclear, there was a good chance that I would not require therapy and although there was no evidence that Hep C could be transmitted by sexual intercourse he advised me to the use of condoms. He also told me not to share toothbrushes and to be careful of spilled blood and to clean the spilled blood with bleach. No other information was provided to me other than what the doctor told me. I was not told how it could be managed and I was not given any medication. I asked if there were any symptoms of Hep C and the doctor said that I would have flu-like symptoms, but nothing serious and it would not affect me for another 20/30 years. I was slightly worried about what the doctor had told me, as I had full care of my daughter and therefore had to be very careful when she was around. However, as the doctor reassured me, I did not think anything of it other than to be careful with sharing a toothbrush and cleaning spilled blood with bleach.

21. In 1994 I was contacted by the hospital to have liver biopsy. I was told that there was slight scarring and fibrosis and I had nothing to worry about. I was also told that they will look at me again in 5 years.

22. In the year 1996 I received a consent form for 'viral surveillance', which I signed and returned back to the hospital. This was the first consent form that I received stating 'From 1985 both Factor VIII and FIX have been sterilized by various methods as far as we are aware there is no longer any risk of transmission of Hepatitis or HIV by these blood products....'. I did not receive this form when I had my operation in 1977 and given FIX or when I was given FIX in 1988 for my knee injury.

23. There is a letter in my medical records from G Alexander to Dr Smith, dated 20 May 1998. The letter confirms that the most likely time that I would have been infected with Hep C was in 1977 when I had the major operation and a massive transfusion was required. The results for Hep C are missing or it was not recorded. The first test results recorded for Hep C were in May 1991.

24. I do not consider that I was provided with adequate information about Hep C and HIV and consider the information should have been provided to me at an earlier date. I consider more information should have been provided in relation to what side-effects, if any, would an individual have.

Advice Given regarding the Risk of Infected Blood Products

25. I was given no information about FIX and I was not given any information about the risks associated with blood products. When I had the major operation in 1977, I was only told by the doctors that I nearly died and I needed a lot of blood.

Section 3. Other Infections

26. To the best of my knowledge I do not believe that I have received any infection or infections other than HCV and HBV as a result of being given infected blood products.

27. To the best of my knowledge I do not believe that I have contracted any other infections including CJD. I do recall my doctor receiving a letter on 30 March 2001. I had discussed CJD with my doctor that day and the doctor said that I am not at risk of CJD because I had not received an 'at risk' batch. However, I received another letter at a later date saying that I may be at risk. I believe this letter was sent to everyone and I do not think it applies to me.

Section 4. Consent

28. I believe that I have been treated and tested without my knowledge, without my consent and without being given adequate or full information. This has been set out in paragraphs 5 and 9 of my witness statement. I believe that I was later tested for Hep C as stated in paragraph 11, but the medical records are not available or it was not recorded. I was again tested for Hep B and Hep C, Liver function tests, HIV in 1991 as stated in paragraph 15 of my witness statement without my knowledge or consent. I was also tested again for Liver function tests, Hep C and HIV on the 15 May 1992. Again these tests were done without my knowledge or consent.

Section 5. Impact

29. I consider I had no physical effects from the infection itself other than being tired by travelling to and from the hospital. I thought about being infected with Hep C everyday when I was first told. I thought to myself that I was just going to the hospital for routine blood tests and check-ups in relation to my haemophilia and now I have ended up in this mess. I was too afraid to get into a relationship as I was worried that if I told them that I had Hep C they would not come near me let alone have sex with me. I therefore did not get into a relationship for that reason.

30. I had my first course of treatment, Interferon and Ribavirin in 2000. When I started this treatment I then realised that Hep C was a very serious virus. This first course of treatment was horrible. My wife left me and I went to live with my mother. I started drinking a lot of alcohol and medical professionals were not happy with me for drinking alcohol. I did feel that this was the only way that I could deal with things. I did manage to stop drinking alcohol. I was told that the treatment in 2000 was not working and so the doctor stopped my treatment.

31. In 2008 I was told that I had cirrhosis/fatty liver and so the doctors put me on another course of treatment. The treatment was called Pegasus and Copegus. Again I was told to stop this treatment as it was not working, but I was told that I would be okay to get a transplant.

32. Generally when I was on the above medication, I started to feel really down. I hated injecting myself and was very nervous when I tried to administer the injection. I spent a lot of time in and out of the hospital and I felt that the hospital appointments were non-stop from 1999 to 2014.
33. When I was diagnosed with cirrhosis I had to have a 6 monthly scan for liver cancer. The scans were traumatic because I dreaded them and I was very worried. I felt that I was always in hospital. Sometimes the doctors would find lesions and make me have an MRI scan. I would have to wait for the results and not able to go home. It was very nerve racking when I was waiting for the results, I had worrying thoughts going through me head.
34. I felt that the medication that I was on made me lose my temper. I found this very difficult especially when my daughter wanted to have her friends round. I did not know how to explain to my daughter what I was going through and the thoughts that were going through my head. I found that I was unable to control my temper. I felt that I suffered from mood swings, which put a strain on mine and my daughter's relationship. I had full care of my daughter. Just after my second course of treatment in 2008, I had to relinquish my daughter to her mother as I was unable to cope with everything that was happening with me. I still have mood swings and I do still have arguments with my daughter. I think this is because of everything that had happened in the past with being infected with Hep C and going through the treatment.
35. When I was on the first and second course of medication, there were periods that my weight would fluctuate a lot. I would lose a lot of weight, and put on a lot of weight. There was a time that my hair had fallen out. My friends and family would ask questions and always tell me that I did not look well. The medication that I was taking orally made me heave all the time and I was unable to eat properly. I always looked as white as a ghost when I was on the treatment.
36. At one stage I was told by the doctors to go on a high fat diet so that the food could take the medication down to my liver, but I hated having to eat like that.

I was unable to get any good night sleeps and some days managed to get about 3/4 hours. I still struggle to sleep through the night and I am always fatigued. When I wake up at night I find it difficult to get back to sleep. All I keep thinking about is what happened to me when I was infected.

37. I was unable to attend work because I was constantly aching and always feel really ill. I am required to climb ladders and roofs as part of my job. As I was unable to work this impacted me financially. I am not working as often as I used to as I am constantly thinking about what happened to me.

38. I have had 3 liver biopsies and I dreaded every appointment. I would attend the hospital feeling okay and then at the appointment they would stick a very long needle in and afterwards I would feel awful. I did try and refuse to have liver biopsies but I was told that it was better and more accurate than having a scan.

39. I went on another course of treatment in 2013. This was my third treatment. Again this treatment was horrible and I suffered similar symptoms as stated above. However, this treatment worked and I have been clear of the virus for approximately 2.5 years.

40. At the time of my second treatment, I had just bought a house and everything was looking up. I had approximately £130k savings. When I started the second treatment I was unable to keep up with the mortgage payments and my savings kept going down and it was all too much to deal with. I had to sell the house and buy a smaller property. I lost money on the house as there was a financial crash, but I had no choice but to sell the house. I then considered that the safest thing to do was to rent somewhere on my own which would give me less responsibilities. I am still currently renting.

41. It was hard to work when all I was thinking about was Hep C. It was always on my mind and I did not think a lot about the business or how to make more money. Everything that I did, always swung back to Hep C. All the hospital appointments that I had throughout the years took over my life. My treatment had to come first before anything else. I feel that I could have done so much

more if I did not have to worry about all of this. Despite this, I consider myself as one of the lucky ones that I did not contract AIDS and am now cleared of Hep C.

42. When I was attending the hospital appointments it was approximately 70 mile roundtrip. I had to attend hospital at least once a month when I was having treatment. When I had the liver biopsies I had to make plans to stay in the hospital and was required to get taxis as parking charges would have been a lot of money.

43. When I found out that I was infected, I kept it hidden for a very long time. I did not talk to anyone about it and kept it to myself, which I found very difficult. I was unable to talk to my mother, who I was living with or any of my friends.

44. I found the doctors to be very offensive. I had an appointment with a doctor in relation to testicular cancer. He put on gloves and mask and made me stand away from him. I told the doctor 'is there is any need for that' and he responded by saying 'I have seen your notes you have Hep C, that's good enough for me... you can die from that you know!'. I did not know how to respond to that comment.

45. When my wife found out that I was infected with Hep C, she panicked and

GRO-C

GRO-C

GRO-C

Section 6. Treatment/Care/Support

46. I have not received any difficulties or obstacles in obtaining treatment, other than the stigma that I received from the doctors, as stated in paragraph 42.

47. I was not offered counselling. If I was, I believe it might have helped.

Section 7. Financial Assistance

48. I received £20,000 from Skipton in or around 2004 as a one-off stage 1 payment. I did not have to apply for it, I just received a letter in the post stating that I would receive a lump sum payment. On acceptance of this payment, I had to sign a document from them to say that I would not take them to Court. Unfortunately, I cannot remember the exact wording.

49. Around 4 years ago I applied for a discretionary top-up from Caxton due to my reduced earnings. I received £360.00 every month. This is reviewed yearly. I have recently received £4,000 and I receive this monthly and get £333.00 a month. I therefore receive £690.00 a month in total.

50. I applied for discretionary payments. The application process was a long process. They required a lot of information from me to include earnings, outgoings etc and I am required to renew the application every year and provide them with the same information.

Anonymity, disclosure and redaction

51. 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.

Statement of Truth

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

Signed...

GRO-C

Dated

15TH NOV 2018

Medical Summary

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

Virology Results

23.04.1985 Hep Bs Antigen-Ria – Not found
Hep Bc Ab-Elisa Anti HBc - Found
Hep Bs Ab-Elisa Anti-HBs - Found
HTLV 111 – Not found
Patient was not told in relation to the above tests. No HCV tests recorded.

19.09.1989 HIV – I – Not found –
No knowledge of the above tests. No HCV tests recorded.

14.05.1991 HCV – Found
Patient was not told about the tests results and was not told he will be having blood tests for HCV.

May 1992 More tests were done, patient was not told.

Significant Entries/Absent Entries

15.12.1977 Medical records from Dr H Matthews to Dr Smith confirming unprovoked epistaxis. He was treated at Bury St Edmunds initially with Factor IX. He was transferred to Cambridge.
Total Factor IX – 41 bottles , i.e 22,960
Blood – 39 units
Platelets – Concentrate from 38 units blood

11.01.1980 Letter from D.G Chalmers to Dr Smith - 2 years since nasal bleeding, checking to see if he has any further bleeding problems since and he would like to see me.

10.10.1984 Letter from Dr Seaman to Mr Varley – re dental treatment – ‘I think it possible therefore that he could have his tooth extraction under cyklokapron cover without any specific factor ix therapy. I do not think we would wish to give him any blood product unless we absolutely have too.... We need only resort to factor ix therapy if you get in to any serious trouble.

20.02.1985 Letter to Mr O’Hora from Dr Seaman, routine blood tests as stated in my letter of January 1985. **The January 1985 letter was not provided to the patient in his copy records.**

12.03.1986 Letter to Mr O’Hora from Dr Seaman – it is not approximately a year since we tested your blood to see whether you had been exposed to the AIDs virus, and you will remember that the test on that occasion was negative.
First time patient was notified of the blood tests in 1985

24.04.1986 Letter to Mr O’Hora from Dr Seaman – blood tests results still negative for antibody to AIDS virus.

20.07.1988 Letter to Mr O’Hora from Dr Seaman – requesting patient to have blood tests for AIDS.

23.01.1990 Letter to Dr Smith from Dr Baglin - Mr O’Hora suffered an episode of haematuria but this ceased spontaneously. Patient given 2 bottles Factor ix.

6.04.1991 Letter to Mr O’Hora to Dr Baglin – my records indicate that you received some factor ix concentrate at this time and I wonder therefore if I cold review you to make sure that all is well.

31.05.1991 Letter to Dr Smith from Dr Baglin – He is on demand hospital treatment and in 1990 received only 1130 units of FIX for an

episode of hematuria. Investigations revealed evidence of past HBV and HCV. – **Patient was not informed of this.**

21.10.1992 Letter from Dr Smith to HDAH, patient says he has HIV annually as part of his normal test for his Christmas Disease. I could find no result of this although I note he is HBV and HCV positive. **Patient was not informed of this.**

27.05.1993 Letter from Dr Richards to Dr Smith – Mr O'Hara has evidence of previous infection with both HBV and HCV. He was not aware of this, but I tried to reassure him that although the overall prognosis was unclear, there is a good chance that he will not require therapy in this regard. **This was the first time the patient was told he had HCV.**

Undated checklist for patients who are HCV positive – written evidence patient informed – 27.05.1993

14.06.1994 Letter from Dr Baglin to Dr Alexander - He received FIX concentrate in 1977 and 1988 and has evidence of exposure to both HCV and HBV.

30.08.1996 Consent form for viral surveillance – **this was the first consent form given by the hospital**

10.04.1989 Letter from Mr Jamieson to Dr Baglin – 'as he is Hep C Positive he will need to go last on the list

12.05.1997 Letter from Dr Baglin to Mr Jamieson – 'Many of our patients with hemophilia and Hep C are undergoing surgery in Addenrooke's and there is no policy that because of their Hep C status they should be last on the list.

20.05.1998

Letter from Dr G Alexander to Dr Smith -the most likely time that he acquired Hep C was in 1977 when he had his carotid artery tied off because of severe epistaxis. A massive transfusion was required.