Witness Name: Robert Moss
Statement No.: WITN7400001
Exhibits:
Dated:

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ROBERT MOSS

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 17 November 2022.

I, Robert Moss, will say as follows: -

Section 1. Introduction

1. My name is Robert Moss. My date of birth is GRO-C 1966 and details of my address are known to the Inquiry. I live in Houston, Texas with my wife and two children, GRO-C who is 15 and GRO-C who is 13. I currently manage services as an IT consultant for other clients, mostly engineering firms and have done so since 2019.

2. I intend to speak about my infection of Chronic Hepatitis C (HCV) and Non-Hodgkin's Marginal Cell Lymphoma through a blood transfusion. In particular, the nature of my illness, how the illness infected me, the treatment received and the impact it had on me and my family's lives together.

3. I was born in London then moved to GRO-C, Wiltshire. My parents divorced whilst we lived there. Following this my mother, sister and I moved in together.

My mother remarried and I now also have a step brother, Phil who is 10 years younger. Initially I worked in the oil and gas industry and then came to the US on a training course. I met my wife at work in Texas whilst being there for 16 weeks. I returned to Norway, where I was originally posted, then I moved to Algeria. In 2000 I quit my job and came to the US and got married in 2001. I then moved to Texas for work."

Section 2. How Affected

4. In the summer of 1985, whilst driving to my friend's house in the countryside in the UK, I went into a hay lorry on a corner and in the accident snapped my right femur. I had a small head injury and my lungs were partially bleeding. I was taken by an ambulance to Oddstock (now known as Salisbury) General Hospital, where I went into surgery to have a steel pin inserted in my right femur running from the hip joint to my knee. This operation was performed by Mr. Carvell, the Orthopaedic Surgeon.

5. During the operation, I was given a blood transfusion and I was kept awake. I don't recall discussing consent or information, I only the remember discomfort. I don't recall having the transfusion or the amount of units given. I was kept awake during the operation due to my head injury. I was under the care of Mr Carvel for a week whilst I was recovering in hospital.

6. I attended daily physio sessions whilst I was in hospital to help with my leg mobility. I recall having to cough every hour whilst seated to get the blood and phlegm out as it was collecting in my lungs. This was uncomfortable and they would massage me afterwards. My recovery took 6-8 weeks before I could move independently without the use of crutches. There was some muscle loss after this recovery period.

7. I have no tattoos and have never taken drugs intravenously. I have not had treatment internationally. I met my wife at 35 and I haven't had many girlfriends or sexual relations.

8. In 1987, I went back to have the steel pin removed from my leg at Oddstock General Hospital. I was anaesthetised at the time and I don't know the amount of units of blood given at this time. However I believe again on this occasion I was given a further blood transfusion. I do not recall discussing consent, risks or other information at that stage.

9. I was not made aware I had Chronic HCV until 2009 when I applied for life insurance with New York Life and they undertook a medical test on me. I was declined Life Assurance due to the findings

10. Someone was in contact later to discuss the findings. I was notified of liver function problems and was advised it could be HCV and saw my Doctor who confirmed through tests that I had HCV.

11. I was shocked and cried and was wondering how much longer I had to live. I wondered whether I would be changing my children's diapers for much longer. I adapted my lifestyle accordingly following research about the HCV infection. I was not given information on how to avoid spreading the infection but I had my own knowledge from this research.

12. I did receive counselling. The person counselling me said that my viral load told them that I had had HCV for a long time. I and the counsellor had a discussion regarding my medical past and through a process of deduction realised that the blood transfusion in 1985 or 1987 were the only ways I could have contracted HCV.

13. My diagnosis did make sense as I was tired a lot, more than I should be and I didn't then know why. I used to have gripping pain in my knuckles at work. A doctor initially diagnosed it as lupus. After testing they realised it was not. This was prior to my HCV diagnosis.

14. I knew I was not as fit and lacked the vitality I sought. I was active at my jobs but could no longer do manual tasks to the same degree I had previously which

was surprising to me. This was a gradual change from 2003 in terms of my fatigue as it became more difficult to get out of bed on a daily basis.

15. My doctors looked at my liver results and said it could be much worse and there was scarring but not a lot. At this point I changed my lifestyle. It took a year to integrate this change entirely. I don't smoke and drink very little. I was told my liver scarring was not cirrhotic and the chances of liver cancer were minimal.

Section 3. Other Infections

16. I am not aware of any other infections I might have acquired from the blood transfusions I received in 1985 and 1987.

Section 4. Consent

17. I don't recall discussing consent, risks or information prior to, or at the time I was given the blood transfusions.

Section 5. Impact

18. My wife was told to get tested upon my HCV diagnosis in 2009. GRO-C was 2 and my wife was pregnant with our daughter GRO-C at the time. Thankfully she was told her results were negative. Our relationship did not suffer as a result of my diagnosis and at that stage we had been married for eight years. My diagnosis did not stop me from achieving my goals in my career. However looking back I feel it did prohibit me from seeing my mum as much as I would have liked to.

19. Since the diagnosis, I have changed my life. I was told it was a problem with my liver, and therefore I became more active. I work out 3 times a week and batch cook my meals 2 weeks in advance, keeping to a nutritional diet. This followed on from my diagnosis in 2009 after searching online for support groups and on how best to improve my lifestyle.

20. In 2014 I underwent a surgical procedure on my nose and had to tell them beforehand that I had HCV as this was on all the medical forms prior to consultation.

21. I did not tell many colleagues or friends about my HCV diagnosis apart from two people. I did not share my information with others because of the stigma associated with this disease and considered it to be my personal business.

22. Upon diagnosis, I found out online that Interferon and Ribavirin were available treatments but not solutions for HCV. I was told it was more likely that I may die with the HCV than from it.

23. The lady counselling me at that time said that the treatments are not great and the odds of a successful treatment were as low as 40%. She said I should wait and see what treatment there was in the pipeline. There was clearly, at that stage developments in this field of medication. She gave me information on various support groups. The groups did not help, as some people had tried the Interferon and Ribavirin treatments once or twice prior, unsuccessfully. I still remember the phrase about dying with it that I saw someone comment on in an online post

24. The Harvoni medication came out in 2013. My friend with HCV was denied this revolutionary treatment by his US insurance company as it was priced at £100,000 for the course. It had however a better success rate, as the other medications which were only treatments, not cures.

25. Initially I was reluctant to try asking for this drug with my insurance company and continued looking after myself through lifestyle changes.

26. In November 2015, I went to my doctor in the US with a Thyroglossal Gland Duct Cyst in my neck. My doctor said it was rare and advised me to speak to an ear nose and throat specialist. The specialist said he would operate on the cyst and attempt to remove the thyroid to prevent further problems in the future.

27. When I went for surgery it was in fact a lymph node that was removed and not a cyst. This lymph node was cancerous and I was diagnosed with Non Hodgkin's Marginal Cell Lymphoma. According to the Lymphoma specialist, Hepatitis C put me squarely in the 'risk bracket' for Marginal Zone Lymphoma, stage four.

28. I was referred to the MD Anderson hospital in Texas and subsequently found out about my Lymphoma diagnosis.

29. From November 2015, my HCV and Non Hodgkin's Marginal Cell Lymphoma was treated with Harvoni through my insurance company as this appeared to them to be economically viable. After 4 weeks, the HCV was undetectable and my viral load was undetected. Upon my final CT scan, the Oncologist said that there appeared to be something in my stomach, which turned out to be cancer, needing 6 courses of chemotherapy treatments.

30. The HCV was treated prior to the Non Hodgkin's Marginal Cell Lymphoma from November 2015. I was then referred to a liver specialist for treatment with Harvoni via a request from my insurance company to treat the cancer and HCV in 2016.

31. Following the treatment, the HCV was, as mentioned previously, undetectable within 4 weeks but I still continued with the full 12 week course. In 2016 the MD Anderson Cancer Centre in Houston, Texas, successfully treated my Hepatitis C and subsequently my Non Hodgkin's Lymphoma. Treatment ended for good in December of 2018 with my last Maintenance Chemotherapy infusion.

32. CAT scans showed that the tumours were fading away. My final scan showed all the stomach tumours to be gone except for one in the stomach which turned out to be Non Hodgkin's Diffused Cell Type which Harvoni does not treat. I then underwent a course of chemotherapy for this. I continued my physical training regime during chemotherapy and changed my life entirely. I had 6 sessions of chemotherapy. After 5 sessions, the workouts became increasing more difficult on my body.

Section 6. Treatment/Care/Support

33. I was provided with counselling as discussed above.

Section 7. Financial Assistance

34. Treatment in the UK did not seem an option as my whole family were then in the US and at the time my work were prepared to look after me and kept me on the payroll, despite my health issues.

35. I had to pay $4,000 every year for 3 years for my medical bills as the treatment is not free in the US, totalling $12,000, as well as other expenses such travel to the hospital etc. This financially impacted upon me and my family. I was never informed that there was financial support for people in my situation as I no longer have much contact with the UK.

36. I did not receive any financial support, compensation or financial assistance from any Trusts or Funds either here or in the UK.

Section 8. Other Issues

37. I have since spoken to a nurse in charge in Ealing and London Central archives trying to find my medical records. I was told they were no longer in Salisbury. I was also told that the records were destroyed due to the passage of time.

Statement of Truth

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

Signed GRO-C

Dated 12/14/2022 14th December 2022