

Witness Name: Bryan Hunter

Statement No.: WITN3083001

Dated; 11/12/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF BRYAN HUNTER

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 24 July 2019.

I, Bryan Hunter, will say as follows: -

Section 1. Introduction

1. My name is name is Bryan Hunter. My date of birth is GRO-C 1947 and my address is known to the Inquiry. I have lived here with my wife for 25 years. I have one daughter who lives half a mile away. I was a medical physics technician and have now been retired for the last 12 years. I retired by choice and was not medically retired.

Section 2. How Infected

2. I was diagnosed with severe haemophilia A when I was 6 months old after I cut my lip and it wouldn't stop bleeding. In those days, whole blood was the only treatment available. In subsequent years I was

treated with fresh frozen plasma, Cryoprecipitate and Factor V111 and it was sometime during this period that I was infected with Hepatitis C.

3. Originally, I was treated at Maryfield Hospital, Dundee, for serious bleeds, for example, if I had a tooth extraction. For most bleeds I stayed at home, staying in bed when necessary, until the bleeding stopped.
4. This was up until 1974 when Ninewells hospital opened in Dundee. Up until about 1992/3 there was no haemophilia centre so if I needed treatment I went to the general medical ward where haematology patients were treated. The only time I was in contact with haematology doctors was when a serious bleed happened. I was off school quite often, usually for periods of 2/3 weeks at a time. My joints have troubled me severely since an early age.
5. I was given fresh frozen plasma in the 1960s at Maryfield hospital by Dr Charles Rizza for a tooth extraction. He actually had medical students running around the hospital grounds first before collecting blood from them as exercise was thought to boost the factor 8 levels! I have also had cryoprecipitate and lots of different brands of Factor V111 over the years.
6. As I used to work in Ninewells, I had an informal agreement that I could just go to the blood bank there and collect Factor V111, when needed, to use at home. I am sure that I was never told that there was any risk associated with using these factor products. In fact, I was so sure that they were safe, I do recall explaining to my mother that there was no risk from all the infusions that I was getting, as I was only being given the clotting factor missing from my blood, nothing else. I never thought that there was a viral risk.
7. I cannot be sure exactly when it happened but I was infected with HCV after being treated with infected blood products for various bleeds. I do not have any tattoos and have never used intravenous drugs.

8. After the establishment of a proper Haemophilia Centre, regular blood clinics were held where blood monitoring was done and I believe that it was at this time (1993) that I was tested for HIV and HCV. I remember Dr Philip Cachia, now Professor Cachia, telling me that my liver function tests suggested I had HCV but I was not infected with HIV. To confirm my HCV status would require a biopsy to measure any damage to my liver but as I was a severe haemophiliac, I felt that this would be too risky. I was told that with HCV I could eventually develop cirrhosis and may in the future require a liver transplant.
9. I vaguely remember being given advice about infection risks like being careful with intimate contact and sharing utensils, but I was not or can't remember being told about the severity of HCV and the likely impact on my life going forward. I didn't realise that it was a life-changing disease. The thing uppermost in my mind was relief that I wasn't going to die of Aids.

Section 3. Other Infections

10. I do not believe that I have received any infection other than HCV as a result of being given infected blood or blood products.

Section 4. Consent

11. NOT RELEVANT From the Penrose Inquiry Final Report, the witness statement of Professor Philip Cachia. In paragraph 34.132, "Dr Cachia found that before he arrived in Ninewells Hospital, HCV tests had been carried out by the virology laboratory on stored frozen blood samples and that there were around 25 haemophilia patients (of around 30 tested) who were HCV positive. Professor Cachia's predecessor in haematology had a list from the virology laboratory of the names of those patients who had tested positive for HCV. It was not immediately clear to Professor Cachia if

patient consent had been obtained for the tests to be conducted. The patients who tested positive had not been told of the results.”

12. I have no way of knowing if my serum was part of these tests, but suspect it was. I do know that I was not aware that testing was being done.

Section 5. Impact

13. The mental effects of being infected with HCV appeared gradually and so were not immediately obvious to me. I suffered from brain fogs and found it increasingly difficult to think through problems, which I believe was a result of the HCV. I worked in the electronic development section of the Medical Physics department of Ninewells hospital and my job was designing and constructing electronic devices and writing computer codes for us in these devices. As time went on, I found it would take me longer to do the design part of my job, especially coding as this requires a lot of abstract thinking.
14. I was studying for a degree in Maths at the Open University. In 1996 I was getting marks in the 80s for the regular assignments done throughout the year but in 1997 my marks gradually fell as the year progressed and they went down to 60s and 40s. You could trace the decline perfectly like it was on a graph. I assumed I was unable to do any better and had reached my limit. I was actually studying two units at the beginning of 1997 but had to give one up to concentrate on the other.
15. At the time, I did not attribute this decline to my HCV. It was not until later during the assessment for transplant that it was explained to me that I was suffering from hepatic encephalopathy and I was given a letter, written by one of the doctors, to send to the Open University to excuse me from sitting my end-of-year exam.

16. At one point, my wife asked one of the specialists in hospital "Where is my husband? I want him back." Everything had slowed down so much.
17. I also suffered for years from tiredness, fatigue, and flu-like symptoms. Again, these developed so gradually, like ageing, that they went unnoticed until I mentioned it at a clinic appointment, when it was explained that these were symptoms of HCV. *His wife says that he lost quite a bit of weight after the diagnosis and before the transplant and that he also had a bit of jaundice.*
18. I was told when I was diagnosed that I may have to have a liver transplant as a result of the damage caused by the HCV, but they couldn't tell me how much damage had happened to my liver because they couldn't do a biopsy. I was monitored fairly frequently as I was using a lot of Factor V111. As I worked in the hospital, I saw Dr Cachia quite frequently and feel he did his best to keep me well and informed of my condition.
19. Eventually, the HCV led to oesophageal varices. These form when scar tissue in the liver blocks blood flow and increases pressure in the portal vein. Blood then flows into smaller veins which can rupture, causing life-threatening bleeding. In a haemophiliac this is obviously very serious. I started getting treatment for this where, using an endoscope they attached small elastic bands over the varices to prevent bleeding. I underwent this unpleasant treatment in June and August of 1997, twice in September and again in October of the same year and each time had to be given Factor VIII to prevent bleeding caused by the procedure.
20. One day in late August 1997 I felt really unwell at work and I went home early. I didn't even have an evening meal, and went straight to bed. My wife, who at the time was a nurse working on night duty left as normal to go to work. The following morning, when I woke up, I felt terrible again and didn't go to work. My wife went to bed as usual but woke some time later and decided to check how I was. She found me delirious and

vomiting blood. It was clear I was having a severe bleed from somewhere but didn't know where. She tried to give me Factor V111 but couldn't as my veins had collapsed. She then called our GP who called an ambulance and I was blue-lighted to hospital. They stopped the ambulance en-route and the technician tried to give me Factor V111 but was also unable to.

21. At the hospital, I assume I was sent for treatment to the endoscopy unit and had my varices banded again. I was in hospital for 6 days. All I remember is during that time, I suffered from confusion and hallucinations and was quite unwell for a few days. I was given Factor V111 and blood transfusions and the symptoms gradually eased. Dr Cachia came to see me and explained that I had had a serious bleed from the varices and told me that I needed to be considered for a liver transplant.

22. I was introduced to a hepatologist, Dr John Dillon, who had previously worked in the transplant unit in Edinburgh, prior to moving to Dundee. He explained what the transplant entailed and how to prepare for one. In October 1997, I was admitted to the transplant ward at the Royal Infirmary, Edinburgh, for a week-long assessment. I had every test you can think of, including a psychological examination, and at the end of the week I was put on the transplant list. Seventeen days later I got the transplant.

23. On 26th October 1997, I got a call to say a liver was available and to make my way to Edinburgh. I remember I was excited as well as nervous and between 8pm and 6am the next day I had my liver transplant. I know from my medical notes that the surgeon wrote "difficult operation" and I had lost 19 litres of blood. So much blood was required that donors were called in to provide extra supplies. I was sent to the high dependency ward and then on to the transplant ward. I remember I was given large amounts of Factor V111.

24. I spent the 3 most miserable weeks of my life in the transplant ward because I felt so weak and bitterly regretted having the operation. It was so bad I said to my wife that if I had a magic wand I would have reversed it. I was sent home for a weekend and I remember I was standing at the end of the drive and thinking that I was going to be blown over, I was so weak. I really just felt I had done the wrong thing. I continued to feel terrible for about one and a half to two months after. I was seriously depressed.
25. I had transfusions in 1993 as part of getting new hips. In fact, I have had 5 hips and 3 knees replaced due to joint problems and had blood transfusions on each occasion, especially on the first lot in 1993.
26. After the liver transplant, I was being monitored to see if the HCV was affecting the new liver. I became unwell again. I was unable to eat, and was thirsty all the time. I was admitted to Edinburgh as an emergency as my blood sugar was so high and was diagnosed with drug induced diabetes, the drug being the anti-rejection drug I must take to prevent organ rejection. I was given insulin immediately and I was on that for about 2 months. However, my levels started to even out and I went off the insulin and onto tablets which I still take today. I am basically on the edge of diabetic. The tablets keep me on the right side of it. Yet another unwanted problem that can be attributed to the effects of the infection.
27. I also had to go back to the hospital two or three times because of jaundice caused by rejection and for biopsies to check the condition of the liver. I returned to work in February and subsequently went on to complete my degree.
28. In December 1998 because of my poor liver function tests, it was decided that the HCV was still active and was attacking my new liver I was started on a six-month course of Interferon and Ribavirin medication. The Interferon was injected and the Ribavirin was in tablet form.

29. After a few weeks on the treatment I was again admitted to Edinburgh because of tiredness and breathlessness as I understand the Ribavirin was destroying my blood cells. I was again given a blood transfusion and the dosage of Ribavirin was halved. After this I coped quite well with the treatment and only suffered with mild flu-like symptoms and feelings of tiredness. However, the treatment did work and I cleared the virus at the end of the course. Since then I have been clear of the virus. I am now monitored once a year by Dr Dillon at Ninewells or occasionally someone from Edinburgh.
30. It has now been 22 years since my transplant and my liver is functioning well. My Factor V111 level is at the lower end of the normal range – above 50%. This is in contrast to the level prior to the transplant of <1%, so I have effectively been cured of haemophilia I have not had a bleed since 1997 and I used to have one almost once a fortnight. I still have trouble climbing stairs but that is a result of the haemophilia and although the damage has been done, there has been no further deterioration.
31. I don't think that there was any treatment that was available and that was withheld from me. I think I've always had exceptional treatment.
32. I have never had any stigma from dentists as I have always had my treatment at a dental hospital or via the haemophilia centre. Every time I have had dentist treatment it has been a terrible experience so I tend not to go to the dentist.
33. I have actually never had any stigma in any form. My family and friends and work have always been aware and have just been incredibly supportive. It has actually amazed me and upset me when I have seen that this is not normal when watching other people's testimonies at the Inquiry.

34. I have never had to give up work and I was paid when I was off (full wages up to 6 months) so I haven't lost anything financially as a result of the HCV.

35. It held back my further educational progression as it delayed my Open University degree but I was able to get it. I didn't go to University after school partly because of the haemophilia and how hard it was to treat at the time. I don't think that HCV or any of its complications has held back or impeded my career progression either.

36. My wife has had it hard looking after my needs when I was having a bleed. If my wife hadn't gotten up that particular morning when my varices bled, I'd have been dead. There is no doubt about that, and there have been a couple of other occasions where she has been there to provide vital help. I think her being a nurse has helped her. My daughter was off to university when I told her about the transplant which scared her a bit but in general she has been fine. She is now a Radiographer in Ninewells. Neither of them has suffered any stigma either and have always been very open about my condition.

37. I worked as a nurse and the day that Brian had to have his transplant I should have been on night duty so I had to rearrange that and take some time off but long-term there was no issues with timing. I don't think it impeded my career progression at all nor have I suffered any stigma. It has had a bit of a psychological impact wondering if I've lost him this time but he's still here.

38. We always used to holiday in the UK because of the haemophilia but when the self-administered Factor V111 came available we were able to travel to the United States and Europe. Insurance was a problem with the haemophilia as it was so expensive, when I became HCV positive I just took the risk and didn't insure myself. With the transplant as well, it is impossible with the insurance now. I don't have life insurance either. We were okay with the mortgage as I didn't declare it.

39. I was quite a sun lover but now have to avoid getting too much sun exposure as I have an increased cancer risk due to the anti-rejection drugs that I must take to avoid rejection.

Section 6. Treatment/Care/Support

40. I have never faced any difficulties or obstacles in obtaining treatment, care and support in consequence of being infected with HCV.

41. I have never been offered any psychological help or treatment for the HCV. I am not sure I would have accepted it at the time as it wouldn't have been the thing to do. I may however, have accepted it in later years. Also, I have had so many things happen that although it sounds silly, I never panic. I just get on with it. You always know as a haemophiliac that you are about to have a severe bleed. You feel it a few hours before. So, anything aside from a bleed didn't really worry me. My wife has also never been offered any counselling despite being there by my side through all of this and holding down a full-time job as well as looking after a family.

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43. I have to say though I was treated very well by the medical profession so I have no complaints. I guess it helped that I worked in the NHS, my treatment has been very good.

Section 7. Financial Assistance

44. The haemophilia nurse told me about the Skipton Fund. She provided the forms and got the doctor to fill them in and there was no difficulty. I

received the stage 1 payment and then monthly payments from Skipton. Now I get them from the SIBSS, which is about £27,000 a year. It was about half that with the Skipton Fund. We have never had a problem with the payments.

45. I don't think that there were any preconditions attached to accepting these payments.

Section 8. Other Issues

46. As far as I'm concerned, the scandal happened as a result of the government trying to save money, being caught out and then trying to avoid responsibility. A wealthy country such as this should never have been in a position where we had to import blood from elsewhere. I don't think that it is any coincidence the payments from the EIBSS went up at the same time as the Inquiry hearings started

47. I should add that I am not legally represented and have never participated in litigation in respect of my diagnosis or treatment.

48. I am not seeking anonymity regarding this matter.

49. I have signed a consent form dated 24 July 2019 allowing the use of my statement and I am aware it will be submitted only once my statement is signed.

Statement of Truth

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

Signed

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Dated

11/12/2019