Witness Name: William Barry
Statement No.: WITN2083001
Exhibits: none
Dated: 15th October 2020

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF WILLIAM BARRY

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 23rd April 2020.

I, William Barry, will say as follows: -

Section 1. Introduction

1. My name is William Barry. My date of birth is GRO-C 1962 and my address is known to the Inquiry. I intend to speak about my experience of becoming infected with hepatitis C. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my family and our lives together.

2. I do not wish to be anonymous for this statement.

Section 2. How Infected

3. I have haemophilia A which was diagnosed when I was ten, around 1972/1973. I received cryoprecipitate to treat this in the past but now receive

Refacto Factor VIII. I have always been treated at the Haemophilia Unit at Ninewells Hospital in Dundee, in relation to my haemophilia.

4. Whenever I had a significant bleed, I would go into the Haemophilia Unit at Ninewells hospital where I would receive cryoprecipitate or latterly Factor VIII to treat the bleed. I had a recurring bleed in my knee from an old football injury and I believe it was during the treatment for that bleed in my knee that I was infected. I received cryoprecipitate to treat this injury. I was treated around three times for that bleed in my knee before I was diagnosed with hepatitis C and it was the only major bleed that I had in the years leading to my diagnosis. I cannot say exactly when I was infected but I was diagnosed with hepatitis C in 1993 so it would have been before that. I believe it was a Dr Tudoch in charge of my care at Ninewells during that time.

5. I was never informed that there could be a risk of infection from receiving these blood products beforehand.

6. I was diagnosed with hepatitis C in 1993, I cannot remember the exact date I was diagnosed. I had gone to my GP at the GRO-C, in GRO-C GRO-C in Dundee, due to a bleed I had in my finger. I cannot remember which doctor I spoke to that day. During that appointment, the doctor mentioned to me in passing, "*I see you have hepatitis C*". I was shocked, I had no idea what this infection was or how I had contracted it. He already knew that I had contracted hepatitis C when I arrived for my appointment, there were no tests performed on the day. I was never made aware that I had been tested for hepatitis C before that appointment. He said it so matter-of-factly, he made it seem as though there was nothing to really worry about. The doctor I saw at the GP did not give me any information about the infection but said I should get in contact with my haematologist at Ninewells to discuss the infection further. I contacted my haematologist, Dr Cachia at the Haemophilia Unit at Ninewells Hospital, who told me that they wanted me and my wife to come in for an appointment. At my appointment, Dr Cachia gave me some further information about the infection. He didn't tell me a lot, only that there was a risk of cross infection and that the infection was very serious.

7. I cannot remember exactly what I was told about the infection at that appointment at Ninewells, but I knew that the infection was something serious just from the way Dr Cachia was talking about it. I remember them saying that the infection could be passed to my wife and that was scary to hear. I don't remember being given a lot of information at that appointment, it was more the seriousness of the infection that was stressed.

8. Looking back I do not think what I was told at that appointment was adequate to help me understand or manage the infection. I really was not given a lot of information at all.

9. I am certain that I could have been told about my infection earlier than I was. My GP already knew that I had contracted hepatitis C when I went in for that appointment about my finger. I have no idea how long they had known about it. If my GP hadn't mentioned it at that appointment there would be no way to tell how long I would have gone without knowing.

10. The way my GP told me about my infection was almost casual, it was very matter of fact. It was not the way I would expect that sort of news to be broken to me.

11. At my appointment with Dr Cachia, I was told there could be a risk of cross infection with my wife but that was basically it. He did not give me any information about how that cross infection could happen.

Section 3. Other Infections

12. I have not contracted any other infections other than hepatitis C from receiving infected blood products. I was tested at one stage for HIV but that test came back negative.

Section 4. Consent

13. I believe I have been tested without my knowledge. As part of my haemophilia treatment, blood would be often be taken from me for testing but they would never tell you what they were testing for. The hospital and my GP both knew about my infection before I did and the only way that could have happened was if I was tested for hepatitis C without my knowledge.

14. I also believe I was tested without my consent simply because I was never asked for my consent in relation to the hepatitis C testing. They performed that test without asking me and without telling me what the test was for.

15. I think I was tested for the purposes of research as well. I just instinctively feel that my infection was something they would want to look into further.

Section 5. Impact

16. Mentally, the infection was a horrific thing to have to deal with. I was constantly worried about infecting my wife and the lack of information I was given only made that worse. I could see that she was very concerned about it as well and that made me worry more. The infection was something that I thought about every single day, it brought me down a lot psychologically.

17. Physically, I did not suffer any of the typical side effects of the infection. The treatment caused some issues but there was nothing before that.

18. The hepatitis C infection has not led to any further medical conditions or complications.

19. I received Interferon and Ribavirin to treat my hepatitis C and I began that treatment almost immediately after my diagnosis in 1993, though I cannot remember the exact date. I received the treatment through Ninewells Hospital under the care of my consultant at the time, Dr Cachia. The treatment was an injection of Interferon and Ribavirin tablet and I was able to take the treatment at home. The treatment was successful and lasted for around a year. I was

given the all clear a few months after I had completed the treatment but I couldn't say exactly when.

20. I did not face any difficulties in accessing the treatment, I was given it almost straight away.

21. I was not aware of there being any other treatments I could have received but the one I was treated with was successful.

22. Throughout the treatment I was worried about whether it would actually work, I never really felt I could be sure. And if it didn't work I didn't know if I would have had any other options, so that fear was a mental torture in itself.

23. The treatment made me feel like I had the flu, the flu symptoms were pretty much constant. It gave me a lot of fatigue as well, I felt tired all the time and that made my mood quite low.

24. I wouldn't say my infection ever had any effect on my treatment for anything else medical or dental. I assume they would take extra precautions but I was never aware of anything significant.

25. My infection put a huge strain on my marriage, I was constantly worried that I could infect my wife. We would take precautions but that didn't mean that the stress of cross infection went away. I also thought a lot about whether I could be a risk to infecting my son. I just felt my family was at risk the whole time. My wife was great with me the whole way through, she never stopped supporting me. She was always behind me and never let me doubt myself. The infection could have ended our relationship but we didn't let it. We didn't tell our son about the infection until he was around twenty one, he constantly worries about my health now. I think my son worries that the infection might come back, and I know that can't be easy to be thinking about all the time.

26. The infection didn't really affect my social life but the treatment definitely changed things a bit. During the treatment, I was so exhausted from all the

side effects that I wasn't really able to do a lot on the weekends or go out with people, it would have been too much.

27. The stigma associated with a hepatitis C diagnosis was something that weighed on me quite a lot. There was always the thought that if anyone found out they would just assume it was from drug use. The stigma around the infection was quite a nasty thing so we kept the information about the infection to ourselves so we wouldn't have to deal with any of that.

28. I had a lot of time off from work because of the infection and the treatment. There were days I just did not feel well a lot of the time so I needed to rest. I wouldn't always take those days as sick days, sometimes I would take them as holidays instead. I just felt bad about having to be off work all the time so I just took them as holidays so I could have more days if I needed. I worked for GRO-C, around the time of my infection and treatment, and that job would involve a lot heavy lifting, moving materials and metal around a lot of the time. I remember I was given a different role because of my fatigue so that I didn't have to lift things as often. My work were really good about it, they gave me the time if I needed it and they knew about my haemophilia as well so they knew it was important for me to treat bleeds right way.

29. The time I did have to take off meant that I did miss out on shift premiums, which meant that I lost out on extra money that I would have been able to earn. Those days off also meant I wasn't able to do as much overtime as I would have wanted and that had a financial impact as well.

30. My parents were devastated when they found out about my infection, I know that must have been very hard for them to hear. They worried constantly about it. GRO-B GRO-B The infection was something I know hit everyone in my family in one way or another. I think as long as they knew the infection wasn't getting any worse, they could make their peace with that, but it definitely affected them.

Section 6. Treatment, Care and Support

31. I have not faced any difficulties in accessing treatment, care or support because of my infection.

32. I was offered counselling at one stage by the Haemophilia Unit at Ninewells because of my infection but I didn't take them up on it. I can't remember exactly when that was but I didn't feel I needed it at the time, I had support from my family and that was enough for me.

Section 7. Financial Assistance

33. I received a lump sum payment of £20,000 from the Skipton Fund some years ago, I cannot remember exactly when. As far as I can remember it was my GRO-B that told me about the Skipton Fund, but I couldn't really say when that would have been. After my GRO-B had told me about it, I asked my nurse at the Haemophilia Unit about how to apply. For the application, I had to fill out some forms and there was a section or a form for the hospital to fill out as well. It was a pretty easy process from what I remember.

34. I have also received some assistance from the Caxton Foundation. They paid for a lot of things that we needed around the house like a washing machine, a tumble dryer, and a fridge. They even got me an iPad so I could track my bleeds and treatments for the bleeds through an app. I think we got all those in the last four or five years. I can't be sure where I heard about the Caxton Foundation but I'm fairly sure it was at one the meetings for Haemophilia Society Scotland. I remember I contacted them and they sent out an application which was a questionnaire. I had to provide them with quotations for things like the fridge or the dryer but that was fairly easy to arrange. Applying for what we needed through the Caxton Foundation was a very easy process.

35. I also receive a monthly payment of around £1,600 from the SIBSS. Those payments began around two or three years ago. I found out about the SIBSS after attending a meeting about the fund in Glasgow, I can't remember exactly

when this meeting was. I think it was Haemophilia Society Scotland that posted a letter to us telling us about this meeting. The application was just another set of forms and I think there was a questionnaire as well. I had no difficulties applying to the fund, it was all very straightforward.

Section 8. Other Issues

36. I have nothing else to bring to the Inquiry's attention.

Statement of Truth

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

Signed GRO-C

Dated 16-11-20