Witness Name: Barclay Bisset Statement No.: WITN2086001

Exhibits: None

Dated: 25<sup>th</sup> June 2020

# INFECTED BLOOD INQUIRY ————— FIRST WRITTEN STATEMENT OF BARCLAY BISSET

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 15<sup>th</sup> May 2020.

I, Barclay Bisset, will say as follows: -

## Section 1. Introduction

- 1. My name is Barclay Bisset. My date of birth is GRO-C 1947 and my address is known to the Inquiry. I am currently single and have been working as an admin officer for GRO-C for over twenty years. 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 life.
- 2. I do not wish to be anonymous for this statement.

## Section 2. How Infected

- I was diagnosed with severe haemophilia A, shortly after birth. I have had long standing treatment with blood products to treat my haemophilia A which I have always received at the Haemophilia Unit at GRO-C Hospital, GRO-C I started to receive cryoprecipitate when it became available in the 1970s, and then latterly Factor VIII produced by the SNBTS, when that became available in the 1980s. I required treatment on a regular basis, typically at least once a month.
- 4. It is impossible to say exactly what treatment caused my infection or when that treatment could have been, but I know I was infected whilst receiving blood products, in response to one of the many serious bleeds I had due to my haemophilia. I would typically only go to the hospital in response to a serious bleed, for example a bleed in one of my joints. I could take treatment at home for anything else. Whenever I had a serious bleed in one of my joints in the to receive cryoprecipitate treatment, this was 1970s, I would go to GRO-C because cryoprecipitate had to be kept at a very low temperature in a freezer and it was too bulky to have been kept anywhere at home. In the 1980s I started to receive freeze dried Factor VIII in response to those more serious bleeds. There were a number of doctors in charge of my care during that period but I remember Dr Tudhope being there for a number of years. Over the years, I have received multiple injections of both cryoprecipitate and Factor VIII to treat bleeds so it would be impossible to say which treatment caused the infection or over which time period I contracted it. However, I can say for certain that it was the receipt of those blood products that led to me contracting hepatitis C.
- I do not believe I was ever given any specific advice about the risk of infection from receiving these blood products. I think it was generally known that there was a risk of infection amongst haemophiliacs and I think that was somewhat accepted at the time. I do not think the risk itself was ever addressed or talked over with me in any detail.
- 6. In the 1980s the biggest concern for haemophiliacs like myself, was whether we could have contracted HIV. I think that was the dominant concern at the

time for both ourselves and the medical profession. I think it would be important to mention that I was tested for HIV in the 1980s and that the test came back negative.

- 7. I was diagnosed with hepatitis C in 1995 during a clinic appointment at the Haemophilia Centre at GRO-C , I cannot remember the exact date of my diagnosis. I was spoken to by the **GRO-D** appointment. When I arrived for my appointment, they already had the information about my hepatitis C result ready and waiting. I had never previously consented to be tested for hepatitis C but the result did not come as too much of a surprise. By 1995, most people who had been receiving blood products like myself had assumed that the tests for hepatitis C would come back positive. I had just personally accepted that would be the result. So, when I did receive my diagnosis in 1995, it didn't come as an enormous surprise, it was almost a forgone conclusion for me at that stage. I think there was an acceptance that all patients in receipt of blood products during the previous twenty years would be HCV positive, and therefore confirmation was almost a formality.
- 8. I did not receive an awful lot of advice at my diagnosis appointment. They did not give me a lot of information.
- 9. Though limited, I would say the information I was given was probably just adequate to manage and understand the infection as far as I can remember.
- 10. In hindsight, I think the information about my infection probably could have been given to me earlier. I think I was informed in line with the period they had elected to tell people about these infections, not the earliest date possible. I'm assuming that because they had my test results before I knew about the infection and that they could have told me earlier. However, regular blood tests were carried out prior to this date including liver function tests and the results were within normal limits so it is t hard to say for sure.

- 11. When they told me about my infection, I wasn't really focusing on how they told me. I just accepted it and tried not to think too much about it. The manner in which I was told of the infection and means of communication were not important to me. The infection wasn't a bombshell for me, in a way I was prepared for it before they told me.
- 12. I cannot remember if I was given any specific information about the risk of cross infection at my diagnosis.

## Section 3. Other Infections

13. I have not contracted any other infections other than hepatitis C as far as I am aware.

# Section 4. Consent

- 14. I do not believe I have ever been treated or tested without my knowledge or consent.
- 15. I do not believe I was ever treated or tested without receiving full and adequate information about what was being done beforehand.
- 16. As far as I am aware, I have never been treated or tested for the purposes of research.

#### Section 5. Impact

17. The mental effects of the infection were considerable. Although I did not experience any physical symptoms because of the infection, there was always the possibility of developing quite acute medical problems. The stress and anxiety of that weighed on my mind. I would have to say that I have been quite fortunate in that I was not experiencing symptoms from the infection but it was something that you knew could develop at any point. The infection was a major cloud over me mentally because I knew that if the infection did develop, the consequences would be quite severe.

- 18. Physically I did not suffer any of the symptoms of a hepatitis C infection, there was nothing I would say I experienced that was directly linked to the infection.

  Although, one can never be sure of things like that.
- 19. To the best of my knowledge I have not developed any further medical complications or conditions as a result of my infection.
- 20. In recent years I was told there was a new antiviral treatment available with very little side effects and I agreed to be treated with that. I started that treatment in April of 2015. The treatment was made available to me through the Haematology Department at GRO-C Hospital. The Treatment was a combination of Harvoni and Ribavirin and the course was three months long. This treatment proved successful. I was given the all clear from hepatitis C at the end of the three months.
- 21. I had no difficulties in accessing treatments. I had previously refused treatment with Interferon due to the many side effects of that treatment but there was no difficulty in accessing it.
- 22. I do not believe there were any other treatments I could have received but did not. I was offered anything that was available to me at the time.
- 23. There were no mental effects from my treatment. Physically there were a few cold and flu-like symptoms. I would often feel unwell and quite fatigued but it did not feel too dissimilar to having the flu.
- 24. My infected status has not had any effect on my treatment for anything else medical or dental.
- 25. I feel that not having any relations and living alone increased my stress and anxiety levels when dealing with my infection. I didn't have people to share my concerns with. At the time I was first diagnosed, you couldn't help but hear stories about people who had contracted infections from blood products in the media. Some of them were quite difficult reading about, and that definitely had a psychological impact on me. It was a time for me where I tried not to let

these reports about other people affect me, as best I could. I tried to stay positive throughout despite what I was hearing from others' stories and personal experiences, but in those circumstances that was quite difficult for me. I tried not to let the infection consciously affect my life as much as possible. As an GRO-C in the local group of the Haemophilia Society, I was in regular contact with people in similar circumstances, and heard at first hand stories, sometimes tragic, about how the infection affected their lives.

- 26. I think I was quite fortunate in that I don't knowingly believe I have ever experienced any stigma relating to the infection. Of course it was always something that was in the back of your mind but I was not affected by the stigma too much directly.
- 27. My infection did not have any impact on my professional life, I was still able to perform my role as I always had and because of that, the infection did not have any significant financial effect on my life.

# Section 6. Treatment, Care and Support

- 28. I have not experienced any difficulties in obtaining treatment care or support because of my infection.
- 29. I have never been offered counselling or psychological support because of my infection. It is difficult to say whether I would have benefitted from that kind of thing if it had been offered but it is possible it could have helped.

#### **Section 7. Financial Assistance**

30. I received an initial one off payment from the Skipton Fund of £20,000 in August 2004. I received a second stage top up payment from the Skipton Fund of £25,000 in April 2011. This was followed by payments of £13,200 per annum. I cannot remember precisely how I found out about the Skipton Fund but I think it would have been through the Haemophilia Society. The application was a series of forms and I believe I had to get supporting information from the Haemophilia Centre Director at GRO-C to supplement

the application. There were no difficulties in applying to the fund as far as I remember, it was very straightforward.

I receive around £27,000 per annum, split into twelve monthly payments from the SIBSS and I started receiving those payments when they first transitioned over from the Skipton Fund in April 2017. I heard about the SIBSS during its transition from the Skipton Fund. I believe everyone in Scotland who had been receiving payments from the Skipton Fund received correspondence that it would now become the SIBSS. I did not have to go through an application process to receive payments from the SIBSS, I believe my details and supporting information was transferred over from the Skipton Fund. I have never had any difficulties in interacting with the SIBSS, they have always been very prompt with payments and correspondence.

# Section 8. Other Issues

32. I have no other matters to bring to the Inquiry's attention.

# Statement of Truth

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

GRO-C Signed

Dated Jun 26, 2020