Witness Name: Gregor McInnes
Statement No.: WITN2847001
Exhibits: None
Dated: 4th March 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF GREGOR McINNES

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 5th November 2018.

I, Gregor McInnes, will say as follows: -

Section 1. Introduction

1. My name is Gregor Kirk McInnes. My date of birth GRO-C 1977 and my address is known to the Inquiry. I am the son of the late John Kirk McInnes. I intend to speak about my father's experience of becoming infected with hepatitis C. In particular, I intend to speak about the nature of his illness, how the illness affected him, the treatment received and the impact it had on him and our lives together.

Section 2. How Affected

2. My father was born on GRO-C 1951.

3. My father suffered from severe haemophilia, type A. He suffered badly with haemophilia as a child. The blood products that he received in order to treat his haemophilia were exclusively Factor VIII.

4. My father was always treated at the Royal infirmary in Edinburgh only. The consultant in charge was Dr/Prof Chris Ludlum. I cannot remember the names of any other doctors because things were not always discussed openly due to the stigma. I do not know exactly the dates when my father might have received any infected blood products.

5. I believe that my father became infected due to contaminated blood products brought in for Factor VIII blood treatment. All haemophiliacs were receiving that at the time.

6. I could not say whether or not my father had been warned of the risk of contracting any infections beforehand. My father and all the other haemophiliacs were eager to engage in a treatment that would improve the quality of life for them. Factor VIII treatment made a difference in terms of not having to spend days hospital, they could simply have their treatment at home.

7. My father was infected with hepatitis C. I think that CJD was mentioned at some point, my father might have been offered a test for this. I could not say 100%, but CJD rings a bell.

8. My sister and I were very much protected from the whole experience of my father becoming infected with hepatitis C. At the time, it was known as the hepatitis non A/non B. We grew up knowing not to go anywhere near my father's sharp equipment such as needles or razors. We were told at some point that there was something else going on, but it was not discussed with us as this was not a matter that was even discussed with friends or family. My sister was born in 1975 and I was born in 1977. We always knew growing up that there

was something going on, but I would not be able to put a date on it. I do not know the circumstances under which my father found out that he was infected with hepatitis C.

9. I am not aware of there being any information or support offered. My mother was a phlebotomist, that is, a blood technician. She probably had a background that enabled her to better to understand what was going on. When my father was infected, the infection hadn't even been classified as hepatitis C, no one knew anything other than the fact that it was an infection and that it was contagious. We were not told anything about it and I believe that my parents wouldn't have kept information from us if they had had it.

10. I do not think that any information was provided in order to understand and manage the infection in terms of daily life. Information must have been provided regarding staying away from sharp equipment and not going anywhere near needles. I remember having this kind of conversations with my father. I knew that the illness affected his liver. I thought that my father would be better off not drinking and joked about this with him. My father didn't want to change his habits and this was something that we would have discussed on occasion, when he went for his regular check-ups. That would have been when I was about 14 years old, in 1990 or 1991, when I would have been old enough to understand about alcohol.

11. I believe that information should have been provided earlier. Even in a standard clinical environment, information was minimal, sparse and very patient-triggered. This means that patients had to specifically prompt the medical staff for it and were rarely offered by the medical staff themselves.

12. I was too young to remember anything about how the results of tests and or information about the infection were communicated to my father.

13. I do not know any details about information that might have been provided regarding the risks of others been infected as a result of my father's infection. I do not think that toothbrushes were an issue, as we were not in the habit of sharing them anyway. I do not actually remember if my father's toothbrush was kept separate.

Section 3. Other Infections

14. My father was only confirmed as being infected with hepatitis C. There was a potential risk of him having caught CJD due to a contaminated supply from an infected donor. Testing was offered, but, as far as I am aware, he chose not to be tested for this as there was no known treatment and the knowledge would be pointless.

Section 4. Consent

15. I believe that my father was treated and tested without his knowledge, without his consent, and without being given adequate and full information. I also believe that my father was probably treated or tested for the purposes of research.

16. I have no proof that this was the case. I have nothing to base these beliefs on other than findings that have come out recently. I personally think that haemophiliacs were tested and treated for the purposes of research. What has come out during the investigation, the knowledge of practices that were going on back then and the time when it was found out that the blood products were contaminated made me believe that they were using haemophiliacs as a control group to see how the disease progressed as no one expected haemophiliacs to live for a very long time anyway.

Section 5. Impact

17. My father never languished with his condition, he had a strong work ethic and worked hard to provide for his family. I do not know much about the mental effects of the illness, my father was part of a generation that didn't talk about feelings. I am sure that the mental effects were more than he let on, but he was not depressive. My father believed that in those circumstances you could either give up or continue to fight, it did not impact his life or his attempts to do things other than in terms of physical limitations. When I say physical limitations, what I mean is that because there was not any treatment when my father was young, he would bleed into his joints and this ended up causing arthritis. His knees, ankles, hips and shoulders were affected. My father was well into his 50s, however, when he started using a walking stick. His physical activities were limited as well due to his haemophilia. We did not play football or run out and about in the garden growing up. He also had limitations in the type of car that he could buy; he needed to get a larger car. Whenever we went on holiday, he had to take the Factor VIII with him and we were often stopped at customs due to carrying sharps and medicines. Apart from that, everything required to be refrigerated. We would have to choose hotels with refrigeration facilities. We would also have to choose hotels with no stairs or cliffs nearby. My father experienced many restrictions in this sense.

18. Due to being infected with hepatitis C, my father developed cirrhosis of the liver. This ended up causing a tumour. He ended up having a liver transplant which had no follow-up and ended up dying of a secondary tumour that hadn't been detected. When my father was young, he was told that he wouldn't make it to age 30, afterwards he was told he would be lucky to make it to 40 and so on. Eventually, he made it to age 60 with a new liver. He ended up being able to meet his grandchildren, who are now growing up without a grandfather. If

my father had not been infected with hepatitis C, his treatment for his haemophilia would have been well under control. My wife was pregnant with our first child at the time of my father's first attempt to have liver transplant. However, on that occasion the liver from the donor was too badly damaged. By the time that my father was able to have a liver transplant, my first son had already been born. As a close family, my father had a high dependency us. I struggled badly as I had to look after a new-born baby as well as looking after my father. My son would wake up in a different place every time that he was put to sleep as there was no sense of calm at that time and everybody was all over the place. The Interferon was successful at keeping the hepatitis C at bay. The liver transplant gave my father 8 more years to live, but there was no follow-up on the part of the medical staff and my father developed a second tumour that was untreatable by the time that they found it. This secondary tumour was on his lungs, but it was linked to the first tumour that he developed in his liver.

19. My father was generally well after his transplant, once he was recovered from the trauma. Afterwards, he had his cataracts removed and this required a great amount of waiting and moving around due to the fact that he had to be the last person to be operated on so that the facilities could be decontaminated. We had a new baby at the time and this was a lot of extra hassle. There were lots of occasions where things were not impossible or constituted extra hassle; I believe that these are the hidden consequences of hepatitis C. My father's hepatitis C was never cured, but eventually it went down to undetectable levels. He was already at that stage. I think the hepatitis C came back at one point, but I am not sure regarding the course of medication that he was on at the time.

20. I do not know many details about the treatments that my father received in order to treat his hepatitis C. My father regularly attended clinics regarding his liver for extra care. I know that he was on quite a few courses of drugs that were trials. Among those, there was

Interferon. Medication had a negative impact on his health, but I wouldn't be able to tell what this medication was or when he took it. His energy levels went down and his general wellbeing was affected. He felt lethargic. These courses of medications were all trials, and he didn't realise how ill he actually felt until he stopped each course of medication. The purpose of the trials was to see what the impact was. Interferon was successful at one point. This might have been around 2006 or 2008. Then the hepatitis C came back, this was in around 2008 and my father must have had the all clear for only about 12 months.

21. I believe that my father received the treatments that were available at the time and he would always go to Edinburgh for these purposes. My Father was self employed so any time off for treatment was time he could not earn. However, there were no cost issues, although I am sure that these treatments were maybe limited to certain candidates.

22. I do not have enough knowledge about the whole situation to know whether or not there were any treatments which ought to be made available that weren't. There was a lot of implied trust from the haemophiliacs on the medical profession, I do not believe that they were as vocal as they should have been and they simply accepted what was given as they were convinced that the medical professionals had their best interests at heart.

23. As for the mental and physical effects of the treatment, my father grew up in household where emotions were not forthcoming. He must have gone through a lot of emotional turmoil, but had trust in those treating him and believed that the right thing was done by the haemophiliacs at the time. I believe that this led to abuse of trust. My father fought the condition the whole way and only gave in right before he died, when he got to the point where everything was too much.

24. My father's infected status affected his cataract operation as he had to wait for a long time due to being required to be the last person to be operated on so that the facilities could be decontaminated. My father had great dental hygiene and I do not believe that his hepatitis C greatly affected his dental treatment. That said, the family dentist at the time was almost like a friend and there might have been a discussion between him and my father. I do remember that we used to go for dental treatment with our mother and that our father would go separately. This might have been due to the fact that he required extra precautions to be taken, but I am not sure.

25. As far as the impact of hepatitis C on our family life is concerned, we did not know any different growing up. It was just what my childhood was like. There were limitations regarding physical activities such as running on the beach and all these extra considerations had to be made regarding things that my father couldn't do as they caused a risk with the potential to cause a bleed. It was almost like a hidden illness. He had a vibrant social circle, but never disclosed the fact that he was infected. His best friend, whom he had been friends with since age 16, only found out about the hepatitis C in the last few years. Even our extended family and friends did not know. My parents did not want other children to be prevented from coming to our house based on an incorrect assumption that they could catch the disease from drinking from a cup or something like that. The hepatitis C really had no impact on our lives due to the fact that it was never discussed. I do remember that when my father's good friend was infected with HIV from infected blood products, it all was kept quiet. The reasons why he passed away were not really disclosed to anyone. My father's friend was a family man and there was a stigma about a straight man being infected with HIV. Later on in time, when Pamela Anderson started talking about her hepatitis C, it seemed that barriers started to be taken down. For us, there was no stigma due to the fact that the illness was never discussed. We were aware that there was a stigma linked to the hepatitis C and that is why we were silent about it.

26. I do not believe that becoming infected with hepatitis C had any educational effects on my father. It was just the haemophilia that had a massive effect on his education.

27. My father was not the kind to time to take time off work due to emotional turmoil. He would just take some time off work to attend clinics and check-ups. He was self-employed so there was no welfare system in place for him; he would not even get benefits. He had to work to provide for his family.

28. Regarding finances, we did not have a lavish life style but we did not want for any of our basic needs. The hepatitis C would have caused some sort of negative impact, but my father worked hard to make up for it and he did not let any of his conditions affect his ability to work. Originally, he was an office clerk and then my grandfather, who was the shop owner, set up another shop with him. They sold clothes for gentlemen. Later on in time, my father owned two pet shops. Then he became a driving instructor when large pet shops came about. My father changed careers in order to maximise his ability to earn.

29. I would not say that the hepatitis C had any effects whatsoever on my own education or career.

Section 6. Treatment/Care/Support

30. I am not aware of whether my father was offered any sort of care, support or counselling as a consequence of being infected with hepatitis C. I was certainly not offered anything.

Section 7. Financial Assistance

31. I know that my father received stage one and stage two payments from the Skipton Fund as he developed complications from his

hepatitis C and qualified for these payments. He also received a payment from the Caxton fund, which was paid out after his death, so my mother received a reduced amount.

32. I think that my father found out that financial assistance was available through the Penrose Inquiry or through the Haemophilia Society, but I am not 100% clear on this.

33. I believe that my father must have received two payments of £20,000 each, from the Skipton fund. These payments were not intended to be compensation, just financial assistance. I believe that my mother is currently receiving £1,400 a month, which is three quarters of the amount my father would have been entitled to, from the Caxton fund.

34. I believe it was my mother who completed all the application forms for financial assistance. Once the forms were filled in, there was no guarantee of eligibility. It was the Haemophilia Society which provided most of the information, but I don't know if there was any help or instructions from any official channels.

35. I do not believe that my father faced any difficulties or obstacles in applying for financial assistance other than the fact that the qualifying factor was that he developed a tumour in his liver.

36. For the Skipton fund, the preconditions where being infected with hepatitis C for stage one and developing complications arising from the infection for stage two. I am not sure what the preconditions might have been for the Caxton fund other than being infected with hepatitis C or HIV.

37. My opinion regarding the amounts received from the trusts or funds is that the process could be very frustrating. The Skipton fund was initiated as a bridge to get people to the end of the Penrose Inquiry. That whole thing was a travesty of justice and process. I believe that the Penrose Inquiry should have been handled completely differently,

especially considering the number of people who were affected and the impact that it had on people and the financial burdens that they had to experience. No amount of money is going to bring my father back. I believe that my mother should be left in a position where she is financially comfortable, and she should be given compensation. I do not believe that there should be any detraction from widows and compensation should be paid either to the estate or to the survivors of deceased people. I also believe that the culprits should be brought to justice.

38. I have not received any compensation myself.

Section 8. Other Issues

39. I believe that the most important matter in this Inquiry is the human cost. It seems that this inquiry is going in the right direction, which is reassuring. I do not want to see a prolonged process, but I understand that there must be a process, it is just frustrating. The more we get into it, the more we find out, like the issue about the missing medical records.

40. My mother is currently waiting to receive copies of my father's medical records. I would not be surprised if parts of those medical records were missing. I know that a section of my father's notes was in my own personal file. This was a large chunk. It might have been due to clerical error, but things like that have happened in the past. We will see in due time whether or not my father's medical records are up-to-date and honest.

41. My father was not involved in the Penrose Inquiry, he was not asked for statement. He was dead by the time that the Penrose Inquiry was completed. My father was also not involved in any litigation regarding his infection with hepatitis C.

42. I get frustrated when I see that issues such as the Grenfell Towers have received a lot more media coverage and there has been a public outcry, but with the infected blood matter, the media has been kept quiet for a long time. Media coverage of this issue has only improved recently.

43. I am happy for my statement be public and do not wish to remain anonymous.

Statement of Truth

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

Signed GRO-C

Dated 03/04/2019