Witness Name: Hugh Campbell MacInnes
Statement No.: WITN2306001
Exhibits: **WITN2306002-005**
Dated: 16th May, 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF HUGH CAMPBELL MACINNES

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

I, Hugh Campbell MacInnes will say as follows:

Section 1. Introduction

1. My name is Hugh Campbell MacInnes. My date of birth is the **GRO-C** **GRO-C** 1957. My address is known to the Inquiry. I am a part-time journalist working for a local newspaper in my community. I am a single man and live with my elderly mother who is 89 years of age. I live in a rural area known as **GRO-C** which is the northern end of the Island of **GRO-C**

2. I can confirm that I have appointed Thompsons solicitors to be my legal representative. I confirm that the inquiry should send all correspondence regarding me to Thompsons.

Section 2. How Infected

3. I was born with severe haemophilia that was discovered when I was a baby. Haemophilia has been genetically passed on through my mother's side of the family for generations. As a child growing up I hated having to go to hospital if I had a bleed. I tended to stay at home and rest if I had a bleed. There were many, many occasions when I would have to go into hospital to be treated if I had a particularly bad bleed. I would be treated normally at GRO-C Hospital, GRO-C however, if the bleed, or complications from the bleed, was serious enough, I would be flown to Inverness and treated at Raigmore Hospital, or the Royal Northern Infirmary. I would also at times be sent from there to Culduthel Hospital, Inverness, if longer convalescence was required. Back then I was treated with cryoprecipitate

4. In 1980 when I was 23 years of age I attended at Raigmore hospital at the invitation of the consultant haematologist Dr Ian Black. He introduced me to home treatment that had become available. This was Factor VIII blood products to help the clotting process. This was far better as it was a much quicker procedure by way of injection. I was taught how to infuse my injection. After this Raigmore hospital sent Factor VIII blood products to the former GRO-C hospital and I would collect them from there to store in my fridge should I need treatment if I had a bleed.

5. I did not attend regular appointments at the haematology department at Raigmore hospital. I cannot recollect being informed that there was a risk of being exposed to infection.

6. As a result of being given contaminated blood products I contracted hepatitis C. When exactly I became infected with hepatitis C remains unclear. Living in a rural area of Scotland, I didn't have regular appointments at the haemophilia centres on the mainland of Scotland until 2007. Prior to that I only ever went to a haemophilia centre (other than due to hospitalisation/admittance) on three occasions. The first

occasion was as indicated in paragraph 4 above. The other two occasions were for medical assessments and some treatment.

7. The second occasion I attended a Haemophilia Centre was in 1985 when I went to Glasgow Royal Infirmary. I went there because I had blood in my urine and also to have my joints assessed. I was kept in hospital for about four weeks. I was having splints on my legs to try and straighten the joints, as well as dental extractions or dental treatment. As a consequence I would be given prophylactic Factor VIII. I was under the care of Dr Forbes at the time. I remember being asked if I would be willing to participate in some research relating to HIV. I agreed to do so. A doctor took a biopsy from my skin and took my bloods. I believe if I had had hepatitis C at that point it would have been picked up. In 2007, I changed my Haemophilia Centre registration from Raigmore Hospital, Inverness to Glasgow Royal Infirmary. I started home treatment on the 15th July 1980.

8. Prior to being formally registered at the Glasgow centre in 2007, the third occasion I attended a haemophilia ward was in 1991. This was at Aberdeen Royal Infirmary and I was under the care of Dr Audrey Dawson. I had been referred to her for a haematuria and a general joint assessment. I was detained in hospital for three weeks during this time I had regular blood taken for testing. I also had many Factor VIII treatments. It was during this period in hospital that my hepatitis C was first detected. However, I was not aware that I had tested hepatitis C positive during my stay in hospital as this was not disclosed to me. There is a letter that was written by the consultant haematologist, Audrey Dawson, to my own GP, Dr Ratchford informing him that I had been tested for hepatitis C and that I was positive. I produce a copy of this letter in evidence and refer to it as **WITN2306002.**

9. As far as I can recall, at no time when I was treating myself at home with Factor VIII products was I ever told that there was a risk of being infected with contaminated blood. During both my stays in hospital in 1985 and

1991 when I was given many treatments and Factor VIIII blood products I was not told beforehand as far as I'm aware about the risk of being exposed to infection.

10. In 1995 I went to my own local GP practice for an unrelated medical matter. I had read in a Haemophilia Society newsletter that 95% of UK haemophiliacs were believed to be infected with hepatitis C. Convinced that I was one of the fortunate 5% that had managed to remain clear, I mentioned it to my GP and sought confirmation during that visit to the clinic. My local doctor was Dr Andrew Ratchford, Habost Clinic in GRO-C GRO-C. He checked my medical records and informed me that I was indeed hepatitis C positive. He said my hepatitis C status had been picked up years earlier during my stay in Aberdeen Royal Infirmary. I was somewhat shocked by this news, to say the least, but on just having received this information I made little fuss and went quietly home to try and process this news. I was shocked that it had been picked up during my stay in hospital in 1991 that I had hepatitis C and I had not been informed of the presence of the virus and had not been advised to consider lifestyle changes to minimise the impact of the hepatitis C infection. I didn't want to voice my frustration too much at the time as I was a patient registered at a single practice, and also he was a good doctor and I believed he was following and NHS guidelines. These guidelines appear to be not to inform patients that they were carrying the infection. This would be to avoid the associated enquiries that would inevitably ensue from anxious patients and the wider public, mitigating against a media backlash. In particular, central government aiming to avoid the additional costs on the NHS of treating patients infected by contaminated blood.

11. My own doctor did not give me any information about hepatitis C. He did however refer me to a gastroenterologist, at Raigmore hospital, Inverness. I went to see Dr Zentler-Munro at Raigmore Hospital. He discussed hepatitis C with me and confirmed that it had been discovered I had the infection in 1991 in Aberdeen Royal infirmary whilst being

investigated for haematuria. Dr Zentler-Munro was very thorough and discussed my condition at length. He discussed the nature, prognosis and management of my condition. He did discuss the risks of others being infected as a result of the infection. There is a letter that was sent to my own doctor regarding my meeting with doctor Zentler-Munro. I produce this letter in evidence and refer to it as **WITN2306003**.

Section 3. Other Infections

12. I do not know if I have received any other infection as a result of being given infected bloods. In 2002 I received a letter from the Highland acute hospitals NHS trust informing me that I was at risk of contracting the vCJD as it had been discovered that someone who had died of vCJD had donated blood between 1987 and 1989. The letter stated that I may have received treatment with a batch of concentrate from this donor. I produce a copy of this letter in evidence and I identify as **WITN2306004**. I also responded to this letter in reply back to Dr Murray the haemophilia director at Raigmore hospital. I produce a copy of my response in evidence and identify it as **WITN2306005**. To date, there is no test for VCJD. It is only discovered if a person starts to develop symptoms or by a post-mortem after death. Nevertheless, I have to live with the knowledge that I could have contracted this fatal infection every day of my life.

Section 4. Consent

13. I do not believe I was tested or treated without my knowledge or consent. As I may have mentioned earlier in this statement I agreed for Dr Forbes to take my blood and conduct a skin biopsy in 1985 when I was a patient at Glasgow Royal infirmary. I remember the research was something about HIV. I was willing to this research to be done for medical advancement.

Section 5. Impact

14. It is hard to know the mental and physical effects of being infected with hepatitis C. Over the years I have suffered with extreme fatigue at times, nausea and flulike symptoms. Whether these were the symptoms of my infection is unclear. My main medical conditions, new joints, are attributed to my haemophilia.

15. I was informed by Dr Zentler-Munro that there was a treatment available for hepatitis C. I was offered this treatment.

16. I started a course of treatment in April 1996, this was for three months. I injected interferon into my stomach, arm or legs three times a week. I was advised to regularly change the injection site to reduce the risk of ulcers forming. This treatment was initially effective but my hepatitis C came back in December, 1996.

17. In 1998 I was offered a second course of treatment for my hepatitis C. This was a treatment consisting of injections of interferon as prescribed and also taking tablets by the name of ribavirin. This treatment thankfully cleared the infection.

18. I consider myself very fortunate that I did not face any difficulties or obstacles in obtaining my treatment despite the fact that it appeared to be a postcode lottery.

19. As a resident in the Western Isles of Scotland I was registered as a patient with the Western Isles Health Board. However, I was being treated by a consultant physician at Raigmore hospital, Inverness, this was part of the Highland Health Board. During the initial assessment and treatment period I was informed that if I had been a Highland Health Board registered patient I would not have received interferon or interferon/ribavirin treatment as the board/trust had not at that time approved its use. I believe this was mainly due to the cost implications.

As a Western Isles Health Board registered patient the consultant had a bit more flexibility in my treatment and was able to proceed with the management of my condition on the basis of medical need and not, as I saw it, a postcode based cost-benefit assessment made by non-medical NHS board members or administrators.

20. I do not believe there were any other treatments available to me at that time for hepatitis C. If there were any of the treatments available I certainly was not informed or offered them.

21. The treatment I received was bearable (considering the potential successful outcome of such treatment) but not particularly pleasant.

22. I did become very fatigued whilst on the treatment. I was also quite nauseous. I remember my skin at times gave a strong chemical odour and it became very tough (more leathery). It became quite difficult to penetrate my skin with an intravenous needle when I was treating myself with Factor VIII

23. I do not believe my infected status impacted upon any other treatment for any other medical or dental care. I know the medical staff were more cautious when dealing with me by wearing gloves and gowning up.

24. Being infected with hepatitis C has had a profound impact on my life. It is at this point that I would like to talk about my first cousin Donald. Donald died at the age of 21 in 1992. He was a haemophiliac and was contaminated with infected blood and contracted hepatitis C and also he developed HIV. The loss of Donald came as a huge personal shock to me that still affects me to this day. Donald was 13 years younger than me, but we got on really well and socialised together. For a few years before his death, I was aware that Donald had contracted the hepatitis C virus. As a keen Glasgow Celtic football fan, I remember his mother once advised me during a visit to his home that the green hand towel in his bedroom was for Donald's exclusive use. I cannot recall if she told

me explicitly that the reason for this was infection control because he had contracted hepatitis C or some other infectious disease. Certainly, I was aware of it, and we must have discussed it briefly at some point, although I cannot fully recall. At this time, during the latter half of the 1980s and early 90s hepatitis and HIV/AIDS were not really subjects that we openly talked about. Unfortunately, and to my disgust later on, I was not aware at this time that I had also been infected with hepatitis C. If I had known about this, I would have been able to discuss the matter more openly with Donald and his family, possibly benefiting from mutual support through a shared condition. He endured his hepatitis C and HIV status without a friend to share it with and the fear of it becoming common knowledge in a close, rural community and the associated stigma that might have ensued could have been to his great disadvantage. I deeply regretted not being informed earlier of my status, in part, so that I could have been of greater support to him and declared myself a fellow sufferer of the condition during his all too brief lifetime.

25. Donald's death also brought vividly home how fortunate it was for me that I had escaped this particularly cruel disease that had robbed us all of a dear friend and relative, with some guilt that I had survived whilst he had not. This remains with me to this day, particularly when I meet his family, as I still regularly do.

26. Contracting hepatitis C made me avoid sexual relationships as I could not take the risk that I may pass the infection onto others. As such, I remain a single man with no children.

27. I am aware of the stigma that surrounds hepatitis C and HIV. Apart from my sister I did not tell anyone of my condition. I live in a close-knit rural community and the stigma associated with my infection was not something I wanted to broadcast I did not even tell my mother.

28. I can vividly recall being in the local pub one night and Donald buying a round of drinks for the table. He accidentally dipped his finger into a frothy pint of ale while passing the drinks to friends. One of them innocently quipped "*careful Donald I don't want to catch aids*". Myself and Donald briefly exchanged glances. In that moment, I somehow knew that we were both fully aware of his HIV status, but it remains something that he couldn't discuss with me. Today, that probably would not have been the case, although even now I suspect it might still have been kept relatively quiet and remained within close family.

29. Incredibly, there remains problems for haemophiliacs infected by contaminated blood where there are still protocols in place to quarantine and isolate patients. I remember Donald's family not being very happy that Donald tended to be given his treatment away from the general outpatients department. He was shunted off and isolated in a side ward within the medical department without a member of staff being present to support him during the treatment. Clearly they were aware of his hepatitis C and HIV status and he was effectively being placed in quarantine.

30. Similarly and incredibly, stigma and ignorance is still evident to this day. Earlier this year, in 2019, I was admitted to Glasgow Royal Infirmary after my prosthetic hip had failed. Initially, I was placed in a bed in a standard six bed surgical trauma ward. However, within 15 minutes, I was approached by a nurse holding a lever arch folder and was asked if I was aware of the condition vCJD and because of my 'at risk' status as a haemophiliac, I was to be placed in a side ward, with my bed duly pushed there. I couldn't believe what was happening as I had attended the same surgical department on two separate occasions in 2014 and 2018 for elective surgery and nothing like this had happened then. I later mentioned it to the haemophilia nurse who was attending me daily and she apologised and said that this should not have happened. I remained in the sideward for 3 to 4 days before being moved to an 11 bed surgical rehabilitation ward

31. The incident earlier this year certainly brought me briefly back to the early 1990s when my cousin Donald, in more dramatic circumstances, had to deal with the stigma and issues of medical quarantine while he was battling hepatitis C and HIV, as well as fear and ignorance within both the medical profession and the wider public.

32. Contracting hepatitis C had little effect on me financially. I did however have to take a lot of time off work when I was on the treatment for the infection due to the debilitating side-effects.

33. Having hepatitis C had little effect on my family members as I kept it private because of the stigma.

Section 6. Treatment/Care/Support

34. I have not faced any difficulties or obstacles in obtaining treatment or care as a consequence of being infected with hepatitis C.

35. I cannot recall being offered counselling or psychological support as a result of contracting hepatitis C, although I may have been.

Section 7. Financial Assistance

36. I found out that financial assistance was available through the haemophilia Society. I applied to the Skipton fund. It would have been in 2005.

37. In 2005 I received a lump sum of £20,000. I have also more recently received a further lump sum of £30,000. This was from the Skipton fund. I also receive a monthly payment of £1500 from the Scottish government's Scottish Infected Blood Support Scheme (SIBSS).

38. I believe the process of applying for financial assistance was relatively straightforward.

39. I do not believe there were any preconditions imposed on the making of an application for financial assistance.

40. The only observation I have regarding the amount of financial assistance I have received is that it in no way compensates me for how having contracted hepatitis C shaped my life. As I have stated, I am single with no family of my own. The amount of money received in no way compensates people who have lost loved ones as a result of being given contaminated blood. That said, at least I was fortunate to have received some financial assistance. Some others like my cousin Donald, who lost his life at 21 years of age, received, as far as I am aware, a single payment from one of the funds prior to his death. His parents or sibling receive no subsequent payment following his tragic loss. The family lost their only son, leaving a sibling (sister).

Section 8. Other issues

41. I have no other matters to raise for the Inquiry.

V1860230

Statement of Truth

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

Signed GRO-C

Dated 12/02/20