Witness Name: LINETTE BIRTLES

Statement No: WITN3226001

Exhibits: 0

Dated: MAY 2019

INFECTED BLOOD INQUIRY

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FIRST	WRITTEN	STATEMENT	OF LINET	TE BIRTLES

I, Linette Birtles, will say as follows:-

Section 1. Introduction

- 1. My name is Linette Birtles. I was born on GRO-C 1982 and I live at GRO-C GRO-C Northern Ireland GRO-C.
- 2. My father, Michael Anthony Birtles (born on GRO-C 1958), was infected with the Hepatitis C Virus (HCV) from contaminated blood products. He died from liver cancer on 9th March 2018, aged 59.
- My sister Laura Birtles has provided a Witness Statement to the Inquiry (Witness Number WITN2880001).
- 4. This witness statement has been prepared without the benefit of access to my father's medical records.

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Section 2. How Affected

- 5. My father had severe Haemophilia A. He was treated at the Belfast Haemophilia Centre initially at the Royal Victoria Hospital (the Royal) and then, when it was relocated, at the Belfast City Hospital (City Hospital). He was under the care of Dr Elizabeth Mayne (Nee Butler) and latterly by Dr Benson.
- 6. My father was one of five siblings. Only two of them had haemophilia, my father and his younger brother, Christopher. My father and my Uncle Christopher were told that they had been infected with HCV in or around 1991. I do not know when they were infected. They had many product treatments at hospital and they then learned how to administer it themselves at home. I thought nothing of seeing my father inject himself with Factor VIII (FVIII) first thing in the morning on an almost daily basis. Uncle Christopher believes that he and my father were infected with non-heat treated 'Edinburgh FVIII', imported/exported between Scotland and Canada. We had a Thatcher government at that time.
- 7. Prior to being informed they had HCV, my father and Uncle Christopher were tested for HIV. They had regular blood tests. The news that my father had HCV came as a shock to him but he was told that it was nothing to worry about and could be treated. My father was not forewarned how serious HCV is and that he might die from it.
- 8. My father and uncle were not warned of the risk of infection before receiving FVIII treatment. They believed that the FVIII was risk free as it was coming from the hospital. They thought the products from the hospital were clean.

Section 3. Other Infections

9. I do not believe that my father had any other infection than that of HCV.

Section 4. Consent

10.1 do not know whether my father was tested or treated without his knowledge or consent.

Section 5. Impact of the Infection

- 11.I do not know the extent to which HCV affected my father's health but his physical health took a sizeable downturn over the years, particularly his last 15 years. He developed chronic asthma and serious respiratory problems. He had arthritis and muscle wastage. His mobility became an issue for him. He was also told that he had colitis in his last few years.
- 12. My father was a healthy man in his younger years. My father lost a lot of weight in the 18 months prior to his death but he said to me that he was okay. The Haemophilia Centre funded my father's trip to Australia in May 2017 to visit my sister, Laura. My father was under the care of Dr MacDougall, Consultant Hepatologist at the Royal. He had an appointment at the City Hospital on his return and was then referred back to the Royal for an urgent scan. He was then told that he was terminally ill with liver cancer. He was informed that the cancer was so far spread that there was nothing they could do. He was however told that they could prolong my father's life and give him a few extra years with radiation treatment.
- 13.1 do not think that my father was properly monitored and/or treated by Dr MacDougall. My father was supposed to have had a (liver) fibroscan in 2016. The scan was cancelled because the machine was broken and his appointment was deferred for a further 6 months. When my father attended the second appointment he was told that the machine was, again, broken. The one in the children's ward would not work either.

- 14. My father was a proud man and insisted upon driving himself to Belfast even though I wanted to take him myself. He starved himself from the night before the first radiation treatment and sat around for hours until the afternoon. He was then told that they were sending him home because they had no free beds and would book him in for 'next week'. On the second attempt, my father mentioned his FVIII ahead of the procedure to be informed that they had no record of him having haemophilia and was sent home again. On the third attempt, my father was told that there was a problem with the radiation line. He was distraught. My father was ultimately given a double dose of radiation because he had to wait so long for it. He was staying with my grandfather and one of my uncles. He drove himself home and was sick for two days. He was so sick from the treatment that it took him around a month before he was up and about. His weight plummeted further. He looked like a 90 year old man.
- 15. In the days before my father's death (on Wednesday 7th March 2018) I took a call from my father's younger brother. My father collapsed whilst out in a shop buying paint (to paint the house) and was taken by ambulance to Altnagelvin Hospital. I remember him being so weak. He said he was tired and sick of it. He told me that he just wanted to sleep. They did more tests and said he was okay and that they were sending him home. I said 'You can't send him home. He doesn't look fine to me' but they insisted on sending him home anyway.
- 16. The next day, I visited with my father and we sat chatting. He had made himself a cup of tea. I stayed with him until he was ready to go to bed. He saw me out and locked the door behind me that that was the last time I saw him alive. He died in the early hours of Friday 9th March 2018.
- 17. My father was very badly let down. I do not believe that my father was told that his liver was deteriorating. The radiation was horrible and the way in which he was treated so unprofessional. If he had had the treatment sooner, it may have helped. It is hard enough that my father was infected with HCV through no fault of his own but to receive such neglect in his final months is awful.

Section 6. Treatment/care/support

- 18. My father had two or three attempts at HCV clearing treatment (tablets or injections) which was unsuccessful. Uncle Christopher had the same treatment. When it didn't work they just got on with it. Uncle Christopher's final attempt worked.
- 19.1 do not believe that any counselling or psychological support was ever made available to my father in consequence of what happened.

Section 7. Financial Assistance

20. My father received Stage 1 payment and (what I believe to have been some sort of) Stage 2 payment from the Skipton Fund. I am uncertain as to whether he received all the money to which he was entitled given his premature death.

Section 8. Other Issues

21. There are no other issues.

Anonymity

22.1 do not wish to remain anonymous and I understand that this statement will be published and disclosed as part of the Inquiry. I do not want to give oral evidence to the Inquiry.

Statement of Truth

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

