

Witness Name: LAURA PAULINE BIRTLES

Statement No: WITN2880001

Exhibits: WITN2880002

Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF LAURA PAULINE BIRTLES

I, Laura Pauline Birtles, will say as follows:-

Section 1. Introduction

1. My name is Laura Pauline Birtles. I was born on [GRO-C] 1985 and I live at [GRO-C] [GRO-C] Perth, Western Australia. I have lived in Perth for almost eight years.
2. My father, Mr 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.
3. This witness statement has been prepared without the benefit of access to my father's medical records.

Section 2. How infected

4. 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 Maine (Nee Butler) and latterly by Dr Benson.

5. My father used Factor VIII (FVIII) concentrate at home on a regular basis as I recall, perhaps daily. My father was disabled with mobility issues. He had metal plates inserted into his knees, the first when he was a child and the second when I was a baby. He was also due an operation on his elbow but passed away before the procedure took place.
6. My father was one of five siblings. Only two of them had haemophilia, my father and his younger brother, Christopher. My father was told that he had been infected with HCV in 1991. My Uncle Christopher found out that he too had HCV at around the same time. I believe they were told that they had both been infected with the same contaminated batch some time in or around 1988 or 1989.
7. I do not know what information was provided at that time as I was just six years old. I know that the diagnosis came as a huge shock to my father and to my Uncle Christopher. My father and Uncle were not warned of the risk of infection before treatment.

Section 3. Other Infections

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

Section 4. Consent

9. I cannot say whether my father was tested or treated without his knowledge or consent as we never discussed the matter. I do not think that he knew that he had been tested for HCV in 1991 when he and my Uncle Christopher were told that they had it because the diagnosis came as a massive shock to him.

Section 5. Impact of the Infection

10. My father's physical health took a sizeable downturn over the years, particularly his last 15 years. I do not know the extent to which HCV affected his health. When I was young, my father was a stronger man. He developed asthma and serious respiratory problems. My parents separated when I was 10 or 11 years old and my sister and I lived with our mother from that time. We lived in a house not far from my father's flat and we saw him most weekends. I remember my sister and I having to call an ambulance on several occasions because of his breathing in or around the time that I was 15 or 16 years old. He would then be admitted to hospital for several days at a time.
11. My father developed colitis, osteoporosis and muscle wastage, particularly to his upper body. He struggled to the extent that he could barely hold a glass of water for any length of time without spilling it. Adaptations were made to his house (to include the toilet) and, eventually, the council installed a wet room shower, but that was a long and hard battle.
12. My father could not bend or straighten his knees and he was unable to stand for long periods of time. If I was taking him out for lunch, I would park my car as near to the restaurant as I could and by the time we had walked inside, he would be tired and needed to sit down. Even driving was difficult for him and he had to switch from a manual to an automatic car to relieve the stress on his joints of having to change gears.
13. I remember my father looking jaundiced on at least one occasion. He had HCV clearing treatment when I was in my early to mid-twenties. It was a trial as I recall as my father put himself forward for it. He had Interferon injections. I do not know how often and over what period of time. My father did not go into detail. He just got on with it. He was that kind of man. The treatment made him sick and he complained of feeling constantly nauseous. His hair changed colour to a far lighter shade.

14. I believe I had relocated to Australia after my father had completed the treatment as I remember him telling me over the telephone that he had cleared the treatment. He was very excited to tell me the news that the treatment had worked but that turned out not to be the case.
15. My father was under the care of Dr MacDougall, Consultant Hepatologist at the Royal. I do not believe that my father was adequately monitored and cared for. My father was diagnosed with liver cancer in December 2017 but it was left undetected for a substantial period of time due to faulty equipment and lengthy waiting times between referrals. 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.
16. I saw my father for the first time in 3 years at the end of May 2017 when he came out to visit me in Australia. I noticed that he was a lot slimmer than before, but he assured me that he felt fine. I assumed that he had lost weight as a result of him having colitis. He stayed with me for 3 weeks.
17. I returned home to the UK in August of that same year and noticed that my father had, in that short period of time, lost an extreme amount of weight. I refer to **Exhibit WITNXXX002** being some photographs of my father clearly his dramatic weight loss at that time. My father told me that he had been trying to get an appointment at the GP surgery but that they were always fully booked. He then organised an appointment at the City Hospital which I attended with him.
18. The doctor who saw him agreed the weight loss was severe and put a red flag on his record for a full body scan on an urgent basis. It was 4 to 5 weeks later when he had the scan and was subsequently informed of his cancer diagnosis, the liver cancer being onset by his HCV. The news of the cancer

diagnosis was a shock to me. I said to my father "You are clear of Hep C" it was then that he told me "No, the treatment didn't work (after all)". My father used to tell me a lot of what he was feeling but always held back a little. He knew it was not easy for me to get back home to Derry if I was worried.

19. My father was told that the cancer would be treated with radiation injections administered to him through a line through his thigh up to his liver. When he arrived at the hospital to have the line fitted, it was not recorded that he had haemophilia (despite the fact that he had been treated at that same hospital for years).

20. My father and I were very close and I was in regular telephone contact with him from Australia. My father told me that, as a result of the omission of haemophilia on the notes, the procedure had to be aborted and there would be a delay of a couple of weeks before the line could be done. After the line was fitted he had to have a further wait for a date for the radiation injection to be administered.

21. I am unsure as to the dates, but, as he lay in the hospital table about to receive the radiation injection, the treatment was again halted. They noticed that the line fitted was faulty and the treatment was again aborted. At this, my father actually broke down. The fear he felt was immense and because of the delays, he knew time was against him. He said that it felt to him that someone or something was trying to sabotage his treatment and kill him. He told me that as he was coming back up from the theatre that day, he could not stop crying; and even the nurse was in tears with him. My father was so distressed and it was equally distressing for me to hear his account of what had happened to him.

22. My father finally had his radiation treatment on 5th December 2017. A different doctor from the previous attempt administered the radiation and he told my father that the line had not strictly been necessary as a means to administer the injection. He went straight into a vein which led to the affected

area. He also administered a double dose because of the delays my father had experienced in receiving his treatment.

23. The unnecessary delay to my father's treatment because of lack of communication between departments and the time lost in fitting a line that was not needed, impacted my father massively. He already had limited mobility and was unable to drive himself anywhere at all for a few days because of the discomfort of the line. A double dose of radiation was also difficult for my father to cope with.

24. My father then experienced unnecessary delay in waiting to find out whether the radiation injections were successful. He waited patiently and I kept ringing to be told by him that they weren't there yet. The day before my father died, I called my father and I was going to book a flight home, but my father told me to wait for the results. He never received any results. He said to me to "wait until the results from the treatment come in. Hopefully they will be here next week and if it isn't good news then come home." Unfortunately he died the night after our conversation. He had gone out to buy paint. He was by then living in a bungalow that had not been properly decorated for the 10 years he had lived there. He may have wanted the place to look nice ahead of his funeral and wake.

25. In the days before my father's death (on Wednesday 7th March 2018) my father collapsed whilst out in a shop and was taken by ambulance to Altnagelvin Hospital. By this stage my father's weight was only 47kg. They kept him in for a few hours and then discharged him. This shocked me as my father was always previously admitted for 3 days. My sister was with my father at that time and she challenged the doctor when my father was discharged. She asked whether it wouldn't be better for him to be kept and monitored but the doctor said it was not necessary and that my father would probably want to go back to the comfort of his own home. At the most vulnerable time in my father's life he was sent home after just a few hours.

26. My father died in the early hours of Friday 9th March 2018. On a Friday my father would visit his own father (my grandfather) but he never showed. One of my uncles was called to the house by a neighbour as two delivery men with a new cooker for my father were unable to get an answer at the door and make the delivery. My father had collapsed in his hallway during the night.
27. On the day of my father's funeral as we entered my father's home, we found a letter from Altnagelvin Hospital that read 'Due to his recent admission to hospital they have reviewed his file and would want a follow up appointment'. My first thoughts were that it was too late (and that he had been wrongly discharged).
28. The whole experience has left our family heartbroken. 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 so awful that I can't even find the right words to explain how I feel. I feel angry, hurt and frustrated because he deserved better. I have a constant ache in my heart because I miss him. I feel helpless because we couldn't do anything to make it better for him. There isn't a day that passes that I don't think about it all.

Section 6. Treatment/care/support

29. My father put himself forward for a treatment trial to clear him from HCV. The treatment was, at first, thought to have been successful but he soon found out that that was not the case.
30. I 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

31. My father received Stage 1 and Stage 2 payments from the Skipton Fund. I was approximately around 17 years old when my father received the Stage 1 ex gratia payment of £20,000. He gave my sister and I £500 each from that

sum. He received the further Stage 2 payment of £40,000 when he was diagnosed with liver cancer. I am unaware of what process he went through to receive this. I believe his visit to me in Australia was also funded.

32. My father struggled financially over the years. I believe that his state benefits were cut. I remember an occasion, around 10 years ago before I went to live in Australia, when my father offered me tea but had no milk in the flat. I went out to buy groceries for him. He should not have had to struggle financially.

Section 8. Other Issues

33. There are no other issues.

Anonymity

34. I 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.

Signed.

GRO-C

Dated

14/04/2019