

Witness Name: CHRISTOPHER BIRTLES

Statement No: WITN3687001

Exhibits: 0

Dated: SEPTEMBER 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF CHRISTOPHER BIRTLES

I, CHRISTOPHER BIRTLES, will say as follows:-

Section 1. Introduction

1. My name is Christopher Birtles. I was born on GRO-C 1963 and I live at GRO-C Northern Ireland GRO-C with my father.
2. I was infected with the Hepatitis C Virus (HCV) from contaminated blood products. This witness statement has been prepared without the benefit of access to my medical records.
3. My brother, Michael Anthony Birtles (born on GRO-C 1958), was infected with HCV from contaminated blood products. He died from liver cancer on 9th March 2018, aged 59. My two nieces Linette Birtles and Laura Pauline Birtles have provided witness statements to the Inquiry under witness numbers WITN3226001 and WITN2880001 respectively.
4. My two cousins, Seamus Charles Conway and Edward Francis Conway, were also infected with HCV from contaminated blood products. Seamus died from

liver cancer within weeks of the death of my brother Michael. Edward has provided his own witness statement to the Inquiry under witness number WITN2738001. GRO-C

Section 2. How infected

5. I have severe Haemophilia A. I 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). I was under the care of Dr Elizabeth Mayne (Nee Butler) and latterly Dr Benson.
6. I was treated with plasma, cryoprecipitate and then non-heated Factor VIII (FVIII) concentrate which I believe came from Scotland and/or America. No advice was given to us beforehand about the risk of infection. Because the FVIII concentrate came from the hospital we thought it was clean.
7. Some time in 1991 Michael and I were called to a meeting at the Royal alongside 8 or 9 fellow haemophiliacs to include my cousin Edward (I cannot remember whether my cousin Seamus was also present). We were told, as a group, by Dr Mayne that we were all infected with HCV. We were told that we had all been infected with the same product at around the same time, some time between 1985 and 1987. I remember thinking that they had known we were infected and had kept quiet for at least four years.
8. Dr Mayne and the other members of her medical staff did not make a big deal about the diagnosis. The news that we were infected was relayed to us in a relaxed and casual manner. They said that they didn't really know what would happen to us going forward. They said that in years to come it might cause liver cirrhosis or cancer but they did not convey to us that it was something to worry about. It was no big deal and/or made to seem urgent. We were not told to abstain from alcohol or change our lifestyle in any way. No advice was given to us about the spread of infection. I'm not even sure if they told us to use condoms.

Section 3. Other Infections

9. In 2004 I received a letter saying I had been exposed to the risk of vCJD.

Section 4. Consent

10. Michael and I were tested for HIV in the early 1980s but we had no idea that we had been tested for HCV at any time. I had no knowledge of the test and did not consent.

Section 5. Impact of the Infection

11. I was never a heavy drinker but I used to go to the pub about twice a week. As stated, no advice was given about lifestyle and alcohol consumption when Michael and I were first given our HCV diagnosis. We were not advised about alcohol for very many years until they started to talk to us about clearing treatment.

12. In 2005 Michael and I had our first treatment of Interferon, which we injected once a week, and Ribavirin tablets, which we took daily. The treatment lasted for 48 weeks and concluded (for me) in March 2006. The treatment made us both sick and I suffered with terrible mood swings. It was unsuccessful for us both.

13. I had HCV Genotype 1 and had another two HCV clearing treatments (which Michael didn't). I had to wait years for more advanced treatments.

14. In 2013 I undertook triple therapy with Pegylated Interferon, Ribavirin and Telaprevir. When I took the medication I would be vomiting within minutes. I also suffer from diabetes complicated by the fact that I was unable to eat and my blood sugar was all over the place. I was only on it for 10 days because the side effects were so bad.

15. In 2016, when the new Harvoni treatment became available, I tried again. I was sceptical at first but said I would give it a go. They had to apply for funding because it cost around £14,000 for a three month course. They were not prepared to give it to everybody because of the cost. That was wrong because the health service had caused the HCV problem in the first place.
16. In January 2017 I was told I had cleared the virus. Dr McDougall and Dr Cash went on to discharge me. I have not had a fibroscan since March 2015 and will request one when I attend my next haemophilia appointment. There is scarring on my liver but I have been assured by Dr McDougall that I do not have cirrhosis. Michael was not adequately monitored and cared for and I now worry about my own health in addition to grieving the loss of my brother.
17. Although I was told that I am clear of HCV, I do not feel the relief that I should feel because I have been told that I still have to disclose it. By way of example I have to tell the dentist that I used to have HCV and they gown up and wear gloves and face masks. Whilst I understand the need for precautions I do not believe other patients are treated with the same level of precaution. I have always used the dentist at Altnagelvin Hospital. I would otherwise be able to go to any dentist I wanted to. I have also been told that I would have to declare having formerly had HCV to a potential employer. If I am clear why do I have to inform them?
18. I worry that I may still have HCV. If it is gone, I worry about it coming back. HCV has affected my whole life on top of having haemophilia.
19. When Michael was diagnosed with liver cancer, it came as a big shock to us all. I went with Michael to his appointments at Belfast Hospital where he was informed that the cancer was so far spread that there was nothing they could do. That said, he was told that they could prolong his life by a few extra years with radiation treatment. The radiation treatment was delayed on numerous occasions. When he finally received treatment he was given a double dose of radiation because he had to wait so long. The double dose made him so sick it was around a month before he was up and about. His weight plummeted

from around 13 and a half stone to around 6 and a half stone. He wasted away to nothing.

20. Michael came to visit us every day. He collapsed a few days before he passed away and was taken to hospital. They discharged him prematurely despite the concerns of his daughter. When he didn't turn up at our home on the morning he died we knew something was very wrong. I rung my brother Paul and he and a neighbour broke in and found him. The next morning a letter arrived from the hospital recalling him back. It was too late.

21. The psychological impact of having HCV has been huge for me. I suffer with chronic fatigue and yet I endure sleepless nights worrying about my health. I suffer with severe anxiety exacerbated by fear of people knowing that I have HCV. I am reluctant to leave home through nerves of the associated stigma. I am depressed but I have resisted taking anti-depressants.

Section 6. Treatment/care/support

22. I was never offered any counselling or support. Michael did not receive the care and support he needed as detailed by his daughters in their respective Statements.

Section 7. Financial Assistance

23. I have received the Stage 1 ex gratia Skipton Fund and also now receive a small income on a monthly basis.

Section 8. Other Issues

24. There are no other issues.

Anonymity, disclosure and redaction

25. I do not wish to remain anonymous and I understand that this Statement will be published and disclosed as part of the Inquiry. I wish 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 .. 28-9-2019