

Witness Name: ERNEST JOHN BIRTLES

Statement No: WITN3686001

Exhibits: 0

Dated: SEPTEMBER 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF ERNEST JOHN BIRTLES

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I, ERNEST JOHN BIRTLES, will say as follows:-

#### Section 1. Introduction

1. My name is Ernest John Birtles. I was born on GRO-C 1935 and I live at GRO-C Northern Ireland GRO-C with my son, Christopher Birtles.
2. My son, Christopher Birtles (born on GRO-C 1963), is infected with the Hepatitis C Virus (HCV) from contaminated blood products. Christopher has provided his own Witness Statement to the Inquiry (WITN3687001).
3. My son, 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.
4. My granddaughters (Michael's daughters), Linette Birtles and Laura Pauline Birtles have provided their own witness statements to the Inquiry under Witness Numbers WITN3226001 and WITN2880001 respectively.

5. My nephew, Seamus Charles Conway (born on 16<sup>th</sup> March 1973), was infected with HCV from contaminated blood products. He died from liver cancer on 28<sup>th</sup> May 2018, aged 45. Another of my nephews (Seamus's brother), Edward Francis Conway (born on GRO-C 1958), is infected with HCV and has provided his own witness statement to the Inquiry under witness number WITN2738001. GRO-C
6. This witness statement has been prepared without the benefit of access to either of my sons' medical records.

## **Section 2. How Affected**

7. Michael and Christopher were both diagnosed with severe Haemophilia A. They were 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) They were under the care of Dr Elizabeth Mayne (Nee Butler) and latterly Dr Benson.
8. They were treated with plasma, cryoprecipitate and then non-heated Factor VIII (FVIII) concentrate which we believe came from Scotland and/or America. Michael and Christopher were two of a group of haemophiliacs called to the Royal some time in 1991 to be informed that they had HCV. The group were told they had probably all been infected by the same product and at around the same time (between 1985 and 1987).
9. My wife, Rita and I had five children in total, all boys. Michael was married and had left home but Christopher came home and relayed to us what had been said by Dr Mayne and her medical team at that group meeting. Christopher had been told it was nothing to worry about as HCV was something that might only cause problems to them some time in the future. Christopher and Michael were told that it was up to them if they told other people that they had HCV but that other people might treat them differently.

10. Some time later and once we all became aware of the risk of the spread of the HCV infection, Christopher ensured that items like his needles and toothbrushes were kept away from us.

11. We were not warned of any risk of infection before the boys started receiving FVIII treatment. We all thought the products from the hospital were clean.

### **Section 3. Other Infections**

12. Christopher received a letter in 2004 saying he had been exposed to the risk of vCJD.

### **Section 4. Consent**

13. Christopher and Michael were tested for HIV/AIDS in the early 1980s. Bloods were taken from them on a regular basis at the Haemophilia Centre. They were both tested for HCV without their knowledge and consent. The news that they had HCV came as a shock to us all.

### **Section 5. Impact of the Infection**

14. When Michael and Christopher found out they had been infected with HCV, we were all devastated. Despite the assurances of Dr Mayne and her medical team. Rita, in particular, was immediately affected. There was a huge/massive change in her. She used to be outgoing and sociable. She used to enjoy going out at the weekend and then all that immediately stopped. She stopped going out. She struggled to sleep at night. She would wake up in the early hours of the morning and pace about the bedroom. Our GP ended up prescribing a morphine solution for her to take at night.

15. We told no-one outside the family because of the stigma. People did not understand. They associate HCV with HIV/AIDS. Rita was overcome with worry and stress. She was literally worried sick. She would isolate herself

and sit and chain smoke. I believe the worry and stress eventually killed her. She died three years ago at aged 79 following a diagnosis of lung cancer.

16. I was also diagnosed with cancer (of the larynx) in 2015. I spent months having radiation treatment at City hospital. I am now clear of it but I think the worry had something to do with my diagnosis.
17. I was upset that neither Michael nor Christopher was given all the facts about how dangerous HCV is. They should have been told how to properly look after themselves. Michael suffered mentally, anxious about people finding out about his infected status. Moreover he was always tired and he then developed a swollen tummy, lost weight and had itchy skin.
18. Michael was diagnosed with liver cancer in December 2017. He was told that his condition was terminal but they could prolong his life and give him a few extra years with radiation treatment. The radiation treatment was delayed on numerous occasions and when he finally received his first dose they gave him a double dose that wiped him out for a month and his weight plummeted further. He waited three months to find out the results of the radiation treatment.
19. Michael would come to visit me every day. One day he did not come out and that set off alarm bells. My son (Paul) and a neighbour went and broke into his back door and found him dead in the hallway where he had collapsed during the night.
20. I harbour a lot of anger and have a lot to say about the death of my beautiful son that I would struggle to convey in one Statement alone. The final insult and annoyance is that my son had to have an autopsy because he was sent home from hospital less than 36 hours before his death, having waited patiently for three months for his radiation results. All the autopsy revealed was that Michael had died from his cancer condition, which I find shocking.

21. I am mistrustful of the medical profession and I worry about Christopher. I can only support him and try to stay positive. He suffers with stress, anxiety and depression.

#### **Section 6. Treatment/care/support**

22. Michael attempted to clear the HCV via tablets and injections but it was unsuccessful. The first treatment made both boys sick. Christopher had three attempts in total at clearing HCV and on his final attempt it was successful.

#### **Section 7. Financial Assistance**

23. Christopher received the Stage 1 Skipton Fund payment and Michael received the Stage 1 and Stage 2 Skipton Fund payments.

#### **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 .....