

Witness Name: EDWARD FRANCIS CONWAY

Statement No: WITN2738001

Exhibits: WITN2738002-4

Dated: APRIL 2019

## INFECTED BLOOD INQUIRY

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### FIRST WRITTEN STATEMENT OF EDWARD FRANCIS CONWAY

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I, EDWARD FRANCIS CONWAY, will say as follows:-

#### Section 1. Introduction

1. My name is Edward Francis Conway. I was born on  1958 and I live at  Northern Ireland  I am a divorcee with two children.
2. I am infected with the Hepatitis C Virus (HCV) from contaminated blood products. My younger brother, Seamus (Shea) Charles Conway (born on 16th March 1973), was also infected with the Hepatitis C Virus (HCV) from contaminated blood products. He died from liver cancer on 28th May 2018, aged 45.
3. I am one of 8 surviving siblings. In order of age, we are Edward (me), John, Maria, Patricia, Paula, Ann, Rosemary and Christina (Tina).

4. Six of my siblings have also provided witness statements to the Inquiry (Witness Numbers WITN2778001, WITN2739001, WITN2964001, WITN2927001 WITN2765001 and WITN2742001).
5. Our cousins Michael and Christopher were also infected with HCV from contaminated blood products. Cousin Michael died from liver cancer on 9<sup>th</sup> March 2018, aged 59. Michael's daughter Laura has provided a witness statement to the Inquiry (WITN2880001).
6. This witness statement has been prepared without the benefit of access to my full medical records.

## **Section 2. How Infected**

7. I have severe haemophilia A. I was treated at the Belfast Haemophilia Centre initially at the Royal Victoria Hospital and then (when it was relocated) at the Belfast City Hospital (City Hospital). I was under the care of Dr Elizabeth Maine (Nee Butler) and Dr Anderson initially and then by Dr McNulty and Dr Benson.
8. I was treated with plasma, cryoglobulin, cryoprecipitate and then then Factor VIII (FVIII) concentrate. A lot of my medical notes and records are missing. There are huge gaps in them and nothing much at all prior to around 1990. Some of the letters written by my doctors contain flippant and misleading comments. Moreover I was previously unaware that Dr Benson had been writing to my GP with reports that my health issues are alcohol related. I am not an alcoholic and have had very little (if any) alcohol at all for approximately 10 years. Before that I was a social drinker albeit I accept that I struggled around the time my marriage ended.
9. There are letters in my (limited) medical notes and records that I have not seen before labelling me as an unreliable attender. I was not copied in. I attend all

the hospital appointments that I am notified of unless there is good reason to have to cancel.

10. Shea and I were told in or around 1984 or 1985 that we had HCV (referred to then as Non-A, Non-B Hepatitis). Dr. **GRO-D** told me but assured me that it was nothing really to worry about. No advice was given before our haemophilia treatment about the risk of infection. Shea and I were in constant communication with each other about our haemophilia. We were told very little how to best manage our infection.

11. Shea and I had Interferon clearing in 1995 for 6 months. The treatment was unsuccessful. I had combined Interferon and Ribavirin treatment for 6 to 8 months. The treatment had bad side effects to include nausea, fatigue and flu-like symptoms. It changed my mood. It brought me down. I still have HCV as I am genotype 1B which is hard to clear.

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

12. I received a letter notifying me that I am at risk of vCJD on 20<sup>th</sup> September 2004.

13. I have been tested on very many occasions for a variety of infections to include the Hepatitis A Virus (HAV), the Hepatitis B Virus (HBV) the Human Immunodeficiency Virus (HIV).

14. The test for HIV was very worrying. My family used to say "Thank God that you and Shea only got HCV and not HIV/AIDS". Little did we know it would end up killing my brother, Shea.

### **Section 4. Consent.**

15. The worry in relation to whether or not I was infected with HIV in the late 1980s was intense. I had no idea that I was tested on so many occasions for so many

infections in the late 1980s and early 1990s. The tests were undertaken without my knowledge and consent.

16. I participated in an Alpha Interferon trial in 1995. I had to self-inject into my stomach.

### **Section 5. Impact**

17. I would just like to say how sad and shocked I am at the respective deaths of my cousin Michael and my young brother Seamus, whom I was extremely close to and loved very much. I also feel very helpless that I could not do anything to stop the progression of his death. Maybe if I had seen signs of the damage caused by Shea's HCV, I could have done something to prevent his death. I never thought there would ever be a health issue arising from the HCV. We were never warned of the dangers. Shea and I constantly communicated about our haemophilia, sharing our concerns and information about anything arising from it. He was my baby brother and I could not help him with HCV. Had I known sooner we may have kept him longer as it was only six months from diagnosis of liver cancer to his young death.

18. In relation to my own health, I have lately been informed that I have cirrhosis of the liver. My understanding is that I may have cancerous liver cells. The issue is under investigation. I have had very many psoriasis outbreaks too.

19. I had a liver ultrasound scan May 2008 and I refer to **Exhibit WIT2738002** being a copy of the Report. I have not had any follow up treatment until very recently despite abnormal liver function results. I was due to have scan in May 2018. The hospital rang me and cancelled it as the scanner had apparently broken. They were going to rebook and send me the details. I rang Tina and let her know straight away as she was due to take me there. I made a 'post it' note of the conversation. I refer to **Exhibit WIT2738003** being a copy letter from the hospital

stating that I failed to attend the appointment in May 2018. It is not true as it was cancelled. The hospital do this a lot.

20. I would say that my short term memory has deteriorated. My long term memory is quite good. I use 'post it' notes to help me remember things. It helps me. I have the full support of my family. I was admitted to A&E at Altnagelvin Hospital in September 2009 with confusion and on the back of that I was sent for an MRI. I am uncertain as to the extent, if at all, HCV (and liver disease) was considered as a possible cause. I refer to **Exhibit WITN2738004** being copy hospital documentation pertaining to the same. My HCV status (and possible liver damage) does not seem to have been relayed. It has been suggested to me that I have vascular dementia. I am now given to understand that there are notes in my hospital records that I have "alcohol amnesic syndrome". I do not accept my cognitive issues to have anything to do with alcohol. My doctors seem to be intent on insisting that I have medical issues related to alcohol abuse. I do not accept that to be the case.

21. The mental anguish is the worst aspect of my condition. I worry all the time. There are days I feel zonked. I wonder what is this that I have and why. I go to bed at night and try to sleep and I cannot, but I am exhausted. I do not know what will happen down the line.

22. I am very private because of the stigma. The doctors told me it was best to keep quiet about the infection but we could tell our family. I have only ever told my very close friends that I have HCV. Apart from our closest friends we have kept the secret of the HCV infection within the family. My own dentist wears a visor and gloves when treating me.

23. Since Shea's death, I have been offered clearing treatment (Epclusa for 12 weeks).

Section 7. Financial Assistance

24. I received a Stage 1 Skipton payment of £20,000 Skipton Fund payments and a monthly income payment. I have had no issues.

Section 8. Other Issues

25. There are no other issues.

Anonymity, disclosure and redaction

26. I am not seeking anonymity and I understand that this Statement will be published and disclosed as part of the Inquiry. I am uncertain as to whether I would 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: 22/04/19