

Witness Name: MARIA CONWAY

Statement No: WITN2739001

Exhibits: WITN2739002-3

Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF MARIA CONWAY

I, MARIA CONWAY, will say as follows:-

Section 1. Introduction

1. My name is Maria Conway. I was born on GRO-C 1961 and I live at GRO-C
GRO-C Derry, Northern Ireland GRO-C
2. My brother, Seamus Charles Conway (born on 16th March 1973), was 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, John, Maria (me), Patricia, Paula, Ann, Rosemary and Christina (Tina).
4. My brother Edward (Eddie) Conway born on 2nd April 1958 is also infected with HCV from contaminated blood products. He has provided his own witness statement to the Inquiry (Witness Number WITN2738001). A further five of our siblings have also provided witness statements to the Inquiry (Witness Numbers

WITN2778001, 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 9th 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 Seamus's full medical records. If and in so far as I have been provided with limited records the relevant entries are set out in the medical chronology at the end of this statement.

Section 2. How Affected

7. Seamus (Shea) had severe Haemophilia A. He 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). He was under the care of Dr Elizabeth Maine (Nee Butler) initially and then by Dr McNulty and Dr Benson.
8. Shea was treated with plasma and Cryoprecipitate at first and then Factor VIII (FVIII) concentrate. He had home treatment from 1984/1985. There is nothing in Shea's medical notes and records to identify the product and batch from which he was infected. A lot of Shea's medical notes are missing. Shea was not aware that he had liver cirrhosis and liver cancer until six months before his death.
9. I was 12 years old when Shea was born. There were so many of us girls and then a boy came along. I understand that Shea was infected with HCV when he was about 11 years old. Dr Maine was Shea's doctor then. Eddie was told around the same sort of time, 1983 to 1985. When I was 15 years old Dr Maine told me at one of Shea's appointments that haemophilia would not affect us girls.

She erroneously told us that we were not carriers. I do not remember HCV being spoken about at any of the appointments. It wasn't something we worried about. I do not know what our parents were told. I think they were told the HCV was something you got because you were a haemophiliac. I remember some time later we were told that infected FVIII would be making the news. We were never told that such harm would be done and that HCV was dangerous to the liver. In fact if I was told Shea was HCV positive in 1984, I had forgotten about it. It was not until around 15 years ago when I heard it mentioned during a hospital visit and was shocked. I think that I knew about Eddie but not Shea. People associate HCV with HIV/AIDS and I think Shea was embarrassed and ashamed. Back in the day, if you said you had HCV people would run a mile from you. They know that it is contagious.

Section 3. Other Infections.

10. Shea received a letter notifying him of the vCJD risk on 20th September 2004.
11. Shea may have been exposed to the Hepatitis B Virus (HBV) in 1992 (but possibly through a vaccine). I understand that he had a lot of blood tests for different forms of hepatitis and for HIV/AIDS.

Section 4. Consent.

12. I do not know whether or not Shea was tested for infection without his knowledge and consent but I remember him being tested for HIV/AIDS on one occasion when he was a lot younger.
13. Eddie was a good age when he was first treated with FVIII but Shea was very young to be treated with FVIII. FVIII was a new miracle treatment from the USA. I think I am correct in thinking that Seamus was the youngest in Northern Ireland

to be treated with FVIII. Given his very young age, I think it quite possible that Shea was used as a guinea pig when he was given it.

Section 5. Impact

14. Shea was a home delivery birth. He was born on a Friday and I first saw him 10 minutes after he was born. He cried a lot and would not settle. It was discovered that he had suffered a bleed into his groin which happened during birth so at just weeks old he was hospitalised and given treatment. That was the start of Seamus getting treatment for his haemophilia. When as an infant crawling, his knees would bleed and he had lots of falls as a toddler. Most of the time he needed treatment. Even when losing his baby teeth he would bleed a lot and need treatment. All dental work was carried out in hospital. As a child he could not understand why he could not take part in a lot of childhood sports or fun and games that other normal children do. This upset him a lot. Because Shea missed a lot of schooling it was decided he would be home schooled 5 times a week just to teach him the basics. He missed out on a better education, play times with other children and making friends.
15. Not only did Seamus miss out a lot in childhood but he also missed out a lot in his teenage and adult years as well due to haemophilia.
16. Shea was ruined and could do nothing wrong. He was allowed to lie out on the sofa because he was sore. If my mother could have put him in a glass bubble she would have. When we got a new house, he had the pick of the bedrooms. He needed a big bed without being bumped and we did not argue.
17. Shea was spoiled by us all. We all gave him money. He was better off than everyone in the family out working. I would lend him £30 on a weekend and he would give it back to me on a Tuesday. I would keep it in my purse folded up

ready to give back to him again at the weekend. We made a joke of it. He was full of banter and back chat.

18. Shea was very sociable and popular. He was a talented amateur snooker and billiard player. He loved snooker. I refer to **Exhibit WITN2739002** being articles printed in the local press after Shea died, a photograph of him pictured with Jimmy White at an event he helped organise and attended on Thursday 17th May 2018 (11 days before his death) and his memorial card. He was a good enough player to have turned professional if it wasn't for his haemophilia.

19. Shea developed breathlessness (and he was a non-smoker). He had a bad cough. He was in severe pain with bouts of vomiting. He lost weight, had a swollen stomach and looked jaundiced. It was a terrible shock to learn that Shea was terminally ill having not been sent for scans. Shea was unaware of any serious liver problems and then cancer until six months before his death. The doctors knew he had liver problems and did nothing.

20. Shea went down hill very quickly. He started having excruciating pain which led to him being hospitalised. We promised our mother that we would look out for him. After he was discharged, my siblings kept a vigil and gave him around the clock care as he was dying. They watched him crying out in pain and despair at leaving his daughter Jenny behind. I was there when he was born and I couldn't handle watching him die. He was adored by us all.

21. My cousin Michael died of liver cancer and his brother Christopher suffers with chronic depression. We are now left feeling fiercely defensive about Eddie's care as Tina has uncovered that he too has liver cirrhosis and are waiting for confirmation of whether he has cancer. We are all affected.

Section 6. Treatment/Care/Support

22. Shea was failed. He was not provided with the treatment and support he needed.

23. I refer to Exhibit WITN2739003 being a letter sent by Dr Benson to Shea's GP on 24th November 2014. He is reported to be treatment naïve due to 'ongoing trouble with alcohol'. For the record, we as a family, do not accept, in any event, the reports therein that Shea was under the influence of excess alcohol when he sustained his leg injuries. I am shocked and upset by reports by Dr Benson to Shea's GP of alcohol being the cause of Shea's cancer.

Section 7. Financial Assistance

24. I understand that Shea received Skipton Fund payments.

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 would like 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 8-5-19

MEDICAL SUMMARY

(This summary is not intended to be exhaustive but sets out key points in the records relevant to the Statement)

This witness statement has been prepared without the benefit of access to Seamus's full medical records.

- 23.12.1985 "During the last year, his mother and Seamus came up several times to the outpatient clinic for tuition in home treatment with Factor VIII." "Seamus has been tested for HTLVIII antibody and is negative." (*Letter Dr Maine to Dr Brady*)
- 08.11.1995 "Seamus has Hepatitis C infection and was PCR positive in July of this year. His sub-group was 3a and therefore suitable for a trial of Alpha Interferon. This was duly instituted but Seamus stopped it without reference to us. Last Friday he told me it made him nauseated and drove him mad. He was also convinced that his hair was falling out." "His last ALT was 187 u/l and I will send you his Friday results when they are available." (*Letter Dr Maine to Dr R Cuthbert*)
- 10.09.1997 "Mr Conway has also been infected with the Hepatitis C Virus as a result of his blood product treatment in the 1980's." "liver enzyme tests remain markedly elevated" "Although his blood tests are rechecked every three months the condition of his liver continues to give cause for concern and would need to be closely observed over the coming years." (*Letter O McNulty, Registrar to Haematology Department*)
- 02.02.2004 "Liver enzymes persistently elevated – needs to be offered combination therapy – needs USS of liver." (*Transfer from plasma-derived to Recombinant factor VIII concentrate Document*)
- 05.08.2004 Stage 1 Skipton Application Form completed
- 20.09.2004 Seamus receives letter notifying him that he may be at risk of vCJD
- Nov 2008 Liver ultrasound scan
- 05.03.2009 Anti-depressants suggested prior to Hepatitis C treatment. (*Letter Dr Benson to Seamus Conway*)
- 17.02.2011 "Seamus denies any alcohol problems". (*Letter Dr Benson to GP*)
- 13.02.2012 GP is asked to "check his bloods specifically in relation to his liver function tests" ... should he "pop in". (*Letter Dr Benson to GP*)

- 07.08.2012 "I remain very much concerned with regard to the state of his liver given both his alcohol intake and his concurrent infection with Hepatitis C." *(Letter Dr Benson to GP)*
- 27.01.2014 "History of chronic alcohol abuse" "His main issue has been ankle oedema which may be related to the fact that he has significant calf muscle wasting or indeed the status of his liver disease". *(Letter Dr Benson to GP)*
- 31.03.2014 "Further to the treatment that he received in the 70's and early 80's he is also unfortunately positive with Hepatitis C". *(Letter Dr Benson to Seamus Conway)*
- 24.11.2014 "Seamus is Hepatitis C positive and is treatment naïve due to his on-going trouble with alcohol". *(Letter Dr Benson to GP)*
- 16.08.2016 Reference to being informed that the Skipton Fund had sent out (compensation) letters (not done by the Haemophilia Centre). *(Letter Dr Benson to GP)*
- 17.10.2017 "Thank you for referring Mr Conway for assessment regarding chronic hepatitis C" "I have explained to Mr Conway that we now have some excellent tablet based therapies" "His alcohol intake is currently approximately six to eight beers on two separate nights per week which he knows is heavier than would be recommended. He admits that his alcohol intake is heavier for three or four years whenever he had a few very significant social pressures" "Investigations: FBP, LFTs, U&E, hepatitis C PCR and confirmation of genotype, ultrasound of abdomen and Fibroscan study". *(Letter Dr McDougall to Dr Benson, cc GP)*
- 15.11.2017 Fibroscan/liver cirrhosis confirmed (liver stiffness measurement 75kPA (IQR 0.7))
- 05.01.2018 "Previous excess alcohol intake" "arranged for blood tests and an ultrasound scan within the next few weeks. I have requested a screening OGD to look for varices. He will be reviewed in six months following his treatment and at this stage, we may ask colleagues in Altnagelvin to take over his hepatoma screening as this would be easier for the patient." *(Letter Dr **GRO-D** SHO to Dr Roger McCrory to GP)*
- 09.02.2018 "Liver cirrhosis secondary to alcohol and Hepatitis C" "Previous alcohol misuse" "Multifocal hepatoma throughout both lobes of the liver with evidence of tumour thrombus extending into the distal right portal veins" *(Letter Dr McCrory to GP).*