

Witness Name: ROSEMARY DEVINE

Statement No: WITN2742001

Exhibits: WITN2742002-3

Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF ROSEMARY DEVINE

I, ROSEMARY DEVINE, will say as follows:-

Section 1. Introduction

1. My name is Rosemary Devine. I was born on 1969 and I live at
 Northern Ireland .
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, Patricia, Paula, Ann, Rosemary (me) 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, WITN2739001, WITN2964001, WITN2927001 and WITN2765001).

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 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. There are huge gaps in them and nothing much at all prior to around 1990. Some of the letters written by his doctors contain flippant and misleading comments. Shea was not aware that he had liver cirrhosis and liver cancer until six months before his death. I lived within very close proximity to Shea. I had a key to his door. I would take Shea his dinner and give him some help around the house. We were very close.

9. I believe Shea to have been around 11 years old when our parents were informed that he had HCV. Dr Maine would have been Shea's doctor then. I am not too sure when Eddie found out that he too had HCV. It may have been around the same sort of time.

10. We (children) were young and we weren't told much at first. I was well into my teens when I realised that Shea had HCV because we were told to be careful if Shea was, for any reason, bleeding. However, we were never, ever told that HCV was dangerous and that Shea was going to die from it. I believed that HCV was fine. I never worried about it. I was more worried about the Haemophilia.

11. I remember my mother saying that Shea was going to be tested for HIV/AIDS. My mother was worried sick about it. Shea would have been old enough to understand what HIV was and my mother, in particular, was terrified for him.

Section 3. Other Infections.

12. Shea received a letter notifying him of the vCJD risk on 20th September 2004.

13. Shea was apparently exposed to the Hepatitis B Virus (HBV) in 1992 (possibly through a vaccine) as there are two Anti-HBs positive test results noted on 28th February and 20th November respectively. Shea was apparently vaccinated against HBV in 1997 and 2004. Shea was vaccinated against the Hepatitis A Virus in May 2005.

Section 4. Consent.

14. I do not know whether or not Shea was tested for infection without his knowledge and consent but his medical notes indicate that he was tested for HIV on quite a few occasions. I do not necessarily believe that Shea would have been aware of

each and every test. He was tested HIV negative in December 1985, on 19th February 1988, 11th November 1989, 23rd October 1990, 3rd December 1990 in February 1992, November 1992 and 19th June 2014. I can only remember being told that Shea was being tested for HIV on the one occasion (when my mother was so worried).

15. Shea participated in an Alpha Interferon trial in 1995. He had to self inject into his stomach. It had horrible side effects and made him very sick and he told me that he didn't think he could finish the course.

Section 5. Impact

16. Shea was our mother's 'blue eyed boy' and we promised to look after him. Shea was the father to one daughter, Jenny (aged 16 years old when Shea died). He idolised his daughter and had wanted to take her on a cruise before he died.

17. Shea was very sociable and popular. He was a talented amateur snooker and billiard player. He loved snooker. I refer to **Exhibit WITN2742002** 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.

18. In latter years, Shea developed a number of health issues to include breathlessness (and he was a non-smoker), loss of appetite, a swollen tummy and jaundice. He began to lose weight. It has transpired that there were issues with Shea's liver markers from the mid 1990s. Shea was not adequately monitored and cared for. Shea was unaware of any serious liver problems until six months before his death.

19. Shea went to his GP in October 2017 with very bad stomach pains and was immediately sent to Belfast City Hospital. He was then backwards and forward to and from Belfast within a relatively short period of time for tests and scans. He was told that his liver markers were elevated and they wanted to make sure there were no tumours. Within that short period of time, he was told that he had liver cirrhosis and then liver cancer. He was then told that there was nothing they could do for him and he was given just three to six months to live.
20. A lot of Shea's medical notes and records are missing but there are some letters addressed to Shea's GP amongst the limited records branding him an alcoholic. Shea was told by his doctors that his 'life style' was to blame (not HCV). Shea took a few drinks every now and then but did not consume alcohol on a regular and/or heavy basis. I was in and out of his home on a daily basis and would have known if Shea was a drinker. Shea was embarrassed to tell anyone that he had HCV. He begged me not to tell anyone. Not even his closest friends knew. I told him that he had nothing to be embarrassed about but it was difficult to get anything out of him. He did not want anyone to know 'his business'. He felt so strongly about it that it that he seemed to prefer his doctors' explanation that he had developed liver cancer from his 'life style' choices.
21. Shea became more reclusive and started to leave his key on his side of the door to stop me getting in. I knew he was in a terrible amount of pain and needed a doctor. He was sent to hospital by our GP at the end of April 2018. At hospital, whilst in excruciating pain, he was treated like an alcoholic or a drug addict. He was asked "is it a fix you are after" because he asked for morphine in his arm.
22. Eddie has been treated in a similar way with reference to alcohol abuse in his medical notes and records. He hasn't had a drink for approximately 10 years. His care has also been neglected with a lack of monitoring and scans. Moreover, after years without a scan, an appointment was made for May 2018 and later cancelled by the hospital. No further scan appointment was sent out and when

Tina chased the hospital they tried to tell her that Eddie had not turned up for the May scan. Eddie suffers with vascular dementia and we have now found out that he, too, has liver cirrhosis (and possibly liver cancer). Eddie was deeply affected by Shea's death. We are left to worry about Eddie and whether he will have to endure the same death as Shea.

23. My brother, Seamus, was the youngest of our family. All through Shea's life he had to suffer with his haemophilia. Growing up life was certainly not easy for Shea or us as he had limitations in what he could do. As a family, my father was the breadwinner and the rest of us took on the role of looking after Shea with our mother. None of us had the opportunity of going to university or to travel as we had to help and give our full support. Even when Shea got HCV, never did I think it would kill him as we were led to believe that he could live as normal a life as possible with HCV. So, to be told that Shea had liver cancer was heart-breaking and to then be told that it was terminal was devastating.

24. To watch a young man have to go through not just his diagnosis but the mental torture of not knowing if he could have some form of treatment as he hoped was a nightmare. As a family, we were never prepared for this. We were never told that Shea's HCV could turn into cancer.

25. Shea went down very quickly. He started having excruciating pain which led to him being hospitalised. We watched him crying out in pain with his doctors not listening to how severe things were. No patient or family should have to go through that. We had to fight to get the right pain relief because they even referenced that he needed some kind of fix because he had asked for morphine. At that stage we had to ring the Haemophilia Centre out of hours to get something done. The Hepatologist who had given Shea his card to call him 'day or night' could not be raised.

26. I was with Shea on that day when he was told that the cancer had spread to his spine leaving him incapable of walking. To watch your youngest brother cry, hug

you and plead with you not to let him die will stay with me forever because I knew that I could not keep that promise.

27. Shea was given radiotherapy for pain relief on his spine and was discharged from hospital on 11th May. Shea had to come home to the care of his family because there was no care package in place for him. He was wheelchair bound and had to be helped washing, dressing and even had to be taken to the bathroom. To watch him lose his dignity like that was awful for him. That last two weeks for Shea's life drastically changed him. He lost all his bodily motions and had to be changed. Family members stayed with him in turn and together for 24 hours per day because he would cry out in his sleep and wake up having nightmare.

28. On the morning of Thursday 24th May my sister phoned me and when I arrived there was a lot of fluid over the bed and floor. He was semi conscious but in a lot of pain. We arranged for the hospice nurse to come out to Shea and she spoke to him about a morphine drive. At this time, he became very scared and aggressive because he knew that it was near the end. On the Friday he agreed for the morphine drive to be fitted because he knew that it was near the end for him. On that day he agreed for the morphine drive to be fitted because he was in so much pain. That for Shea and us was a horrible day. Shea remained semi conscious but was still in a lot of pain until the Sunday when the doctor said that he needed a stronger dose. That is when we knew Shea had less than 24 hours left. On 28th May at 12.48 am we said goodbye to our youngest member of our family, our brother, and our friend.

29. I will never get over the trauma of watching him fight his upmost only to lose the battle in such a short space of time. We only had a few months of Shea being diagnosed until his death. Having to watch your youngest sibling fight and die a horrible death will stay with us as a family forever. The impact of Shea's death has left us heartbroken. Having already lost our cousin Michael Birtles to the

same disease just before Shea died and watching my eldest brother Eddie living with HCV and not knowing what is going to happen is terrifying.

Section 6. Treatment/Care/Support

30. Shea was failed. He was not provided with the treatment and support he needed. Shea had just one (failed) attempt at clearing HCV in 1995. Thereafter it was left untreated despite the recorded concerns in relation to liver damage.

31. I refer to **Exhibit WITN2742003** 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.

Section 7. Financial Assistance

32. Shea had a Stage 1 Skipton payment of £20,000 in or around 2004. He received a Stage 2 Skipton payment just before he died. I believe he received a monthly income payment of something in the region of £1,500. As key holder to Shea's home I would go in and out and brought his mail to him when he was in hospital. He told me to open his mail (a bank statement) and referred to the money as "that is what I am getting for dying" and wouldn't be any use to him. I was trying to keep his spirits up and said "It's there for you to enjoy when you get out (of hospital)".

Section 8. Other Issues

33. Our family has been profoundly affected by this scandal. I have three daughters who are carriers, one granddaughter and a grandson on the way. My daughter is

due to give birth to a baby boy in four weeks so she has to deliver in Belfast in case he has haemophilia. So, we still have to deal with Belfast Hospital.

Anonymity, disclosure and redaction

34. 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

27-4-2019

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)*.