

Witness Name: PAULA MCLAUGHLIN

Statement No: WITN2927001

Exhibits: WITN2927002-3

Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PAULA MCLAUGHLIN

I, PAULA MCLAUGHLIN, will say as follows:-

Section 1. Introduction

1. My name is Paula McLaughlin. I was born on 1963 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 (me), Ann, Rosemary (Rosie) and Christina (Tina).
4. My brother Edward (Eddie) Conway born on 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, 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 Cryoprecipitate at first and then Factor VIII (FVIII) concentrate. He had home treatment from 1984/1985. I don't know when Shea was given the bad batch of blood. I think he was contaminated before he was 10 or 11 because that is when he was told. 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.
9. I believe that Eddie was told that he had HCV around the same sort of time as Shea. Dr Maine was the doctor at the time.

10. I remember my mother being worried sick about HIV/AIDS. HIV/AIDS was a new thing in the news and it scared the life out of everyone. Seamus then got the all clear.

11. Shea was really worried about the stigma associated with having HCV. He was embarrassed and did not want anyone to know about it. He became wary about the risk of infecting others too. I remember a nurse in A&E forgetting to attach the rubber bung to the cannula in Shea's wrist. His blood was gushing and he shouted at me "Don't touch me". He was very family orientated and so caring and brave. He told me "I don't want to be a burden". I said "You are not".

Section 3. Other Infections.

12. Shea received a letter notifying him of the vCJD risk on 20th September 2004. My son, Emmett, is a haemophiliac and he received that letter at around the same time. Emmett was still at primary school at the time.

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 Shea

being being tested for HIV on the one occasion (when my mother was so worried).

15. I understand that Shea participated in an Alpha Interferon trial. He did not finish the course because of the side effects but no further treatment was offered to him.

Section 5. Impact

16. Seamus was my mother and father's golden child. If they could have wrapped him in bubble wrap they would have. Shea was a character. He was very witty and funny. He loved life despite all his challenges and he was ruined by us all. He doted on his 16 year old daughter Jenny. He talked about her a lot. He always referred to her as "my Jenny".

17. Seamus started to complain of feeling unwell for about a year before he died. He was breathless and he had a cough. He was not a smoker. He started to lose weight. He came into my work in October or November 2017 and told me that he might have cancer. He said that his doctors had said there was a problem with his liver and were investigating the possible presence of "little tumours". It all started from there. His GP had referred him for tests. He was not aware of any liver problems before then. I said "No don't be silly" but he told my sisters the same thing. I met him in M&S a short time later and he told me that the cancer diagnosis was confirmed and it was terminal. He was told before Christmas. I am sure that his cancer diagnosis was confirmed before Christmas because he wanted to wait until after the Christening of one of Patricia's grandchildren before telling Patricia. The Christening took place before Christmas.

18. Shea wanted to do more with his family. He wanted to go on a cruise and have a big family meal. My Emmett was due to get married on 3rd August 2018. Shea was looking forward to the wedding. Shea was admitted to hospital at the end of

April in horrendous pain. We had to fight for the appropriate pain relief for him. The hospital staff did not know he was a haemophiliac. We rang City Hospital out of hours to try and get hold of Dr Benson and then Dr McCrory. The out of hours doctor eventually agreed to putting him through another scan and I said "not without pain relief first". They gave Shea morphine as he was being wheeled into the lift and he was sick everywhere. I had to go out to Matalan to buy pillows. Seamus needed a pillow between his legs to take the pressure off his joints. He tried to maintain his humour for the benefit of the younger ones. He joked to my Emmett that he would be getting the pillows back as a wedding present.

19. The scan revealed that the cancer had spread to Shea's spine. Whilst in hospital having radiotherapy Shea said "I don't think I can get to the wedding". His longevity was going round and round in his head. He was in terrible mental anguish. I tried to keep his spirits up and told him that if he didn't feel up to it, he could come along to the meal afterwards. He was very protective of Emmett and Tina's son, Luke (both haemophiliacs). He would say to me "make sure they know this won't happen to them".

20. Shea's death was awful and it happened so quickly. He was discharged from hospital and we (his siblings) gave him 24 hour care with the MacMillan Nurses coming in throughout out the day. When I came to sit with him I heard Shea roaring when I approached the flat. He was in such horrific pain that he could not be touched to be turned. On one occasion I was pushed out of the flat by the nurse because I was so distressed. I could still hear Shea through the open window squealing in pain. On another occasion I grabbed the visiting doctor by the arm and told him "you have to do something".

21. When the nurses came knocking with the morphine drive, Tina and Rosie were taking a quick break and a cup of tea at Rosie's home. I knew it was the end and I thought "Oh my God, what am I going to do now?" He held my hand and just

said "thanks" to the nurse. On the Saturday he was in and out of consciousness then he died on Sunday morning.

22. Shea was a talented amateur snooker and billiard player. He loved snooker and could have turned professional if it wasn't for his haemophilia. I refer to **Exhibit WITN2927002** 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. Seamus was very popular and so many people asked for his memorial card that our brother, John, had to print more. Everyone knew him in the community and his funeral was huge. The snooker men did a Guard of Honour. So many people attended.

23. A big part of our life is now missing. On the day of Emmett's wedding we all smiled and made sure he had the best day he could but inside our hearts were breaking. Shea is sorely missed by everyone.

24. Eddie was devastated by Shea's death. He cried. We have recently found out that Eddie has cirrhosis of the liver and we are left wondering if Eddie will have to go through the same ordeal as Shea.

Section 6. Treatment/Care/Support

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

26. I refer to **Exhibit WITN2927003** 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

27. Shea had payments from the Skipton Fund. When he was dying he came into the shop and asked me to help him complete an application form for what he called the "death money". He had so many plans with Jenny and did not get to enjoy it.

Section 8. Other Issues

Final Thoughts

28. On 28th May 2018, I lost my baby brother Seamus to cancer which occurred as a result of contaminated blood products. I am totally devastated as it was very difficult to watch him at the end of his life and how he suffered terribly. Seamus was a very funny and strongminded character, sorely missed everyday. He suffered all his life with Haemophilia A and fought so hard to stay alive. Seamus was a very talented snooker player but unfortunately due to his ill health he could never pursue it. Seamus always had mobility problems due to his haemophilia and his treatment led to his contamination.

29. I feel very angry and let down at the negligence of the people who were supposed to look after Seamus. This negligence has caused a great loss in our family. I feel very guilty as his sister that I was the one there when the morphine drive was administered knowing that this meant the end of Seamus' life. It was also very upsetting to have to tell my son who is also a haemophiliac about Seamus' prognosis.

30. The contaminated blood scandal is referred to as historic but it is affecting us in the here and now. As well as losing my cousin, Michael Birtles, just before Seamus, my brother Eddie is also infected with HCV. It has been extremely

distressing having to write going over the memories as it is bringing back bad memories of when he was admitted to hospital in excruciating pain and the medical staff did not help. Seamus was discharged without a treatment plan in place. It was up to myself and other siblings to look after him until Seamus untimely death at 45 years old.

Anonymity, disclosure and redaction

31. 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... 28-4-2019.

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)*.