

Witness Name: JOHN CONWAY

Statement No: WITN2964001

Exhibits: WITN2964002-3

Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF JOHN CONWAY

I, JOHN CONWAY, will say as follows:-

Section 1. Introduction

1. My name is John Conway. I was born on GRO-C 1959 and I live at GRO-C
GRO-C Northern Ireland GRO-C I work for Johnson Press (the distributors for 14 local newspapers throughout 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 (me), Maria, Patricia, Paula, Ann, Rosemary (Rosie) and Christina (Tina).
4. My brother Edward (Eddie) Conway born on GRO-C 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, 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 Cryoprecipitate at first and then Factor VIII (FVIII) concentrate. He had home treatment from 1984/1985. Shea was not aware that he had liver cirrhosis and liver cancer until six months before his death.
9. I believe Shea was 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 but it was around the same sort of time. Shea was young when he learned he had HCV and his head was all over the place. He was afraid of the stigma not the infection. His very close friends

only knew much later in life. They just knew he was "a bleeder". My mother said that Shea was panicking in case it gets out. I think he would have been tested for HIV, but I don't know.

Section 3. Other Infections.

10. Shea received a letter notifying him of the vCJD risk on 20th September 2004. I am not aware of any other infections. I obtained Shea's medical notes but have not been able to bring myself to read them in any detail.

Section 4. Consent.

11. I do not know whether or not Shea was tested for infection without his knowledge and consent. He was young when he was treated with FVIII and he may have been used as a guinea pig for research.

12. 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. He abandoned the treatment as a result.

Section 5. Impact

13. Seamus was the baby of the family and because of his condition my mother and father spoilt him. Seamus had more money than the people in the house that were working. If you were taking him anywhere my mother would say "be careful with him in crowds". You had to keep him away from anything dangerous but it was difficult. You could not keep him in. He had to live his life.

14. Shea loved football but could not do it with haemophilia. He took up snooker which he was very good at. He played Alex Higgins and Jimmy White in charity

matches. He won the North West Amateur Championship. We were all proud of him. He could have turned professional but it would have meant him moving away and my mother would not have had that as he needed our care.

15. I refer to **Exhibit WITN2964002** 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 (printed by me at work).

16. Shea was ruined by us all. He knew he could call on us to do anything at the drop of a hat. He would ask Rosie to flatten (iron) a waist coat for him five minutes before he had to leave for a snooker match (even though she was busy making tea for her family) and would call me up at work and ask me to publish results and articles after the paper deadline. Everything was just dropped on you. You could have throttled him at times but now I wish I was getting those calls.

17. My partner, Bernie, was very close to Seamus. Shea was the life and soul and was easy to have a great crack with. He would always have a joke or a remark to make to Bernie about her dinners. Everybody would have banter with Seamus. When he walked into a room he would always stop and have a conversation with you. He was always joking. Eddie is the same.

18. Seamus and I would meet and have a few pints when Liverpool was playing. I knew Seamus had HCV but he did not like to talk about it and I did not want to delve too deeply into it with him. When he arrived at my house in November 2017 and said that he had tumour on his liver I did not know what to think. He was always upbeat; you never saw him too down. Over the Christmas period he phoned me saying I must come to your house for my tea. He told me then that he was terminally ill and had 3 to 6 months to live. I don't know what I said. I was speechless.

19. Shea started talking about going on a cruise. I had shown him photos of Bernie and me on a cruise and he wanted to take his daughter, Jenny. He then started talking about a big family cruise, a big family holiday with everyone invited along. I told him that we would do it but he deteriorated so quickly that we did not get to go.

20. His main worry and concern was his daughter. Jenny lives with her mother and GRO-C Jenny is a lively head strong 16 year old girl. Shea made sure she had toiletries, money in her pocket and clothes. He ensured that her phone was topped up and we as a family were at her disposal if she needed a taxi set up to go out and get home at weekends. Jenny was keen on McDonalds and Shea would always take her there. Rosie cooked for Seamus but he also enjoyed take-away food. I don't use it myself but I always got to hear through Facebook where Shea and Jenny were whilst out eating. Shea was not aware of any issue with his liver. He was not given any advice about what to eat.

21. When Shea's health plummeted and he was admitted to hospital in April 2018, the hospital staff were awful to him. I was so angry at how he was treated. One lady doctor more or less said to him that they can't waste time and resources on street drunks. I was shocked. We had a wheel chair for Shea. He was in excruciating pain and could not walk or even lie flat. I wanted to lift him up and take him out of the hospital when I heard that. I had no idea that Shea had ever been labelled as a drunk. It was the fault of that doctor's profession that he had HCV and liver cancer from contaminated blood. Shea was an occasional social drinker and not a drunk. He mostly drank with me and I don't have cancer!

22. The young doctor in A&E Altnagelvin Hospital would not accept that Shea had anything other than a bleed despite Shea trying to explain it wasn't a bleed "I know what a bleed feels like". Shea was asking for appropriate pain relief given his haemophilia and liver condition. We were unable to get hold of Dr Benson or Dr McCrory. Eventually Dr Benson sent word through a duty doctor at the

Haemophilia Centre that if Shea said it was not a bleed then more than likely it wasn't. The young doctor apologised to Shea when he was discharged from A&E saying "I should have listened to you young lad because you are right it was not a bleed".

23. We found out after Shea was eventually taken for a scan that the tumour had spread to Shea's spine and he had to have five blasts of radiotherapy to do nothing more than ease his pain and try to give him some mobility. Dr Benson came up to Shea's room with two others on the day he was discharged from hospital. He had a haemophilia clinic at Altnagelvin that day. The solicitors I had organised for Shea to make a Will had just left. Dr Benson sat at the end of the bed and it was difficult for me to watch Dr Benson lean in and shake Shea's hand.
24. Over the last couple of weeks of Shea's life, we had plans to watch the European Cup Final together. Neither of us saw it. I sat by Shea's bedside and he drifted in and out of sleep. If he heard cheers, he lifted his head and said "Liverpool must have scored' and then he would go back to sleep.
25. It was a surreal to be there watching over Shea when he was dying and then he was dead. I do not know how it happened. You always think you can wave a magic wand and it will not happen and then it does. He would cry and say that he did not want to die because of Jennifer. I had no answer, we could just say 'It will be alright' but of course it wasn't alright.
26. I am 14 years older than Seamus. I never thought I would have to arrange Seamus' funeral. He should have done that for me.
27. I have nothing substantial to prove it, but I feel that Shea's prognosis was kept secret from him until it was too late. There was so much Seamus wanted to do but we ran out of time because they did not tell us his life was ending. It was just sprung on him.

28. We want the truth about Seamus and Eddie. Whatever the situation with Eddie is, we need to know. All we know at present is that Eddie has a cluster of cancer cells. We don't know what that means and what we should be doing to watch and protect him. We just want a little bit of honesty and respect.

29. We are afraid of terrifying Eddie and we did not want him to see the way Seamus was. I am terrified for Eddie wondering if the same thing is going to happen to him. I could have done with Eddie's support when Seamus was dying but we could not let him see what Seamus was suffering.

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. He was given just one ultrasound scan in 2008. Thereafter it was left untreated despite the recorded concerns in relation to liver damage.

31. I refer to **Exhibit WITN2964003** 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 received Stage 1 and Stage 2 Skipton payments. He only received the Stage 2 Skipton payment just before he died. He wanted Jenny to be the sole beneficiary of his estate.

Section 8. Other Issues

Final Thoughts

33. Throughout his very short time with us, Seamus had a very poor quality of life with haemophilia and associated conditions spending quite a long time in hospitals and attending hospitals as an outpatient.

34. As a young boy this had a major impact on his schooling and his social life. His attendance at school was very poor due to his condition. He was never ever able to be employed in any job. Seamus loved football but was not able to take part in any contact sport because of his condition. Snooker was his first sporting interest. However this was not without limitations also as it sometimes resulted in bleeds in his arm and leg joints. He played at a very high amateur level and was well known in the North West of Ireland for his ability but could not take this to a higher level because of his condition.

35. It seems so unfair that my younger brother having faced so many challenges with haemophilia should then contract HCV through contaminated blood. This compounded his medical condition and further complicated his social life. There was a period when he had some stability for a couple of years which led to the birth of his daughter but even that relationship broke down after a couple of years.

36. In the months leading up to Seamus passing away all his conversations with me were about looking out for his young daughter. He really doted on her and made sure she wanted for nothing. There was so much they wanted to do together and so unfair that she is now left without a father.

37. When both my parents were passing away the last words they spoke to me was to look out for Seamus. He was the baby of the house and it is so difficult coming to terms with his death. It is as if time has stood still for the entire family. Nobody seems to want to do anything because Seamus won't be there. How do you watch out for something like this? I feel so frustrated because I feel the family did follow my parents instructions. He was the baby of the family and so popular.

38. It is so hard to accept that I will not be going for a beer ever again with my younger brother, talking football (we both supported Liverpool) or listening to his awful jokes. Making sure I got all his photos and snooker articles printed in the local where I work.

39. I feel so disappointed that I could not take him on his last holiday. He asked me to go on a cruise with him and his daughter but time ran out as his health deteriorated. In the months leading up to his death watching him suffer was not something I was prepared for. Even now I am still handling Seamus' affairs and I feel so depressed and hurt by what happened. I really don't think I have got a good night's sleep since he passed away. Every time I look at his picture on my mantelpiece I get flash backs to all the good times and bad times we had together and then I feel so angry. This should never have happened.

Anonymity, disclosure and redaction

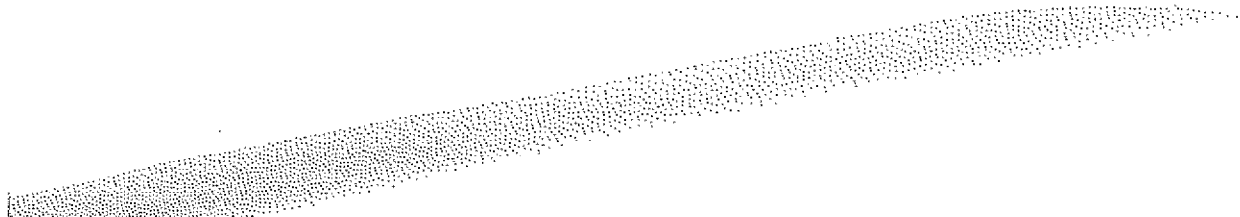
40. I am not seeking anonymity and I understand that this Statement will be published and disclosed as part of the Inquiry. I would like to give oral evidence to the Inquiry.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C

Dated 30-4-19



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).*