

Witness Name: PATRICIA KELLY

Statement No: WITN2765001

Exhibits: WITN2765002-3

Dated: APRIL 2019

INFECTED BLOOD INQUIRY

FIRST WRITTEN STATEMENT OF PATRICIA KELLY

I, PATRICIA KELLY, will say as follows:-

Section 1. Introduction

1. My name is Patricia Kelly. I was born on [GRO-C] 1962 and I live at [GRO-C] [GRO-C] 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 (me), Paula, Ann, Rosemary 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, WITN2964001, WITN2927001 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. 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.

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. Eddie was married and was told at around the same the same sort of time.
10. I do not believe our parents and brothers were given any advice about the risk of infection from FVIII before treatment. It was hailed as a wonder, miracle drug.
11. My mother died in 2008. She went to her grave ignorant as to just how serious HCV is. She was never given reason to worry about Seamus having HCV. She thought HCV to be a sort of side effect of FVIII treatment. Our parents thought that because Shea and Eddie were clear of HIV they would be alright. My mother was also very protective of Shea (and Eddie) and did not want them stigmatised and outcast. My mother was very private and would not have wanted anyone looking at us differently. She never even told anyone when our father contracted MRSA in hospital. She had a positive outlook and saw no problem with HCV apart from stigma.
12. Seamus had a series of 4 broken bones, the last being his femur approximately five years ago. In retrospect I believe his brittle bones/lack of bone density to be associated with HCV/liver damage. He had to have an operation on his femur and stayed with me when he was discharged from hospital. There is a lot of ignorance about haemophilia (even in the medical profession). Shea was I believe the first haemophiliac to be operated on at Altnagelvin Hospital, Derry. The surgeon performing the operation was a nervous wreck. His hand was shaking drawing a diagram of the femur for Shea. In terms of HCV, Shea was always isolated, placed in a side hospital room to himself.
13. Shea was very particular whilst with me at my home that he had his own towels (to be washed separately) and that we stayed clear of his things including his yellow sharps bin. Other than that he did not want to talk about HCV. Shea was

embarrassed that he had HCV. I believe he too was worried about the associated stigma. We were not allowed to tell anyone. I was fighting for him to get ground floor accommodation. He told me I was not to tell the assessor coming to visit that he had HCV. I said "It's not your fault, you did nothing wrong" but he remained adamant.

Section 3. Other Infections.

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

15. Tina and I saw that Shea was exposed to the Hepatitis B Virus (HBV) in 1992 (although possibly through a vaccine). Shea was vaccinated against the Hepatitis A Virus in May 2005.

Section 4. Consent.

16. 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. 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 did not know that Shea was being tested for HIV on a continuous basis.

17. 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 could not finish the course.

Section 5. Impact

18. Shea was a talented amateur snooker and billiard player. He loved snooker. I refer to **Exhibit WITN2765002** 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 was not adequately monitored and cared for. He had just one liver ultrasound scan in 2008 and was unaware of the issues with his liver as set out in the Chronology at the end of this Statement. He had a Fibroscan in November 2017 after he went to his GP complaining of stomach pain and having lost weight. He was unaware of any serious liver problems until then.
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 saying that alcohol has caused him to develop liver disease. Shea was told by his doctors that his 'life style' was to blame, not HCV. When Shea told me he was dying I could not believe it and told him "no, you have got that wrong". I could not accept it.
21. Shea organised his own funeral two weeks before he died. He had a new Liverpool Football Shirt that he wanted to be buried in and chose "You'll never walk alone" to be played. His greatest loves were Liverpool Football Club, Jenny (his daughter) and snooker. He loved life. Seamus did not want to die. We, his family, are now his voice.
22. Shea was the second youngest of 10 children. The youngest, Marguerite, died in childhood. Severe haemophilia A is a serious condition for any child to come to terms with. As his sister, I am so angry that his life was ended the way it did. I find it hard to accept his death as he was treated in his home with the utmost

respect to this condition. He was the golden child, ruined by us all. The running joke in the family home was that he had his own glass box and nobody was allowed to breathe wrong on him. My mother and father had a lot of stress to deal with as my older brother, Eddie, was also a haemophiliac. Most of Eddie and Shea's childhood years were spent in hospital and they were given around the clock care and consideration from us all. They could never attend school and ride a bike or play normal games. They couldn't hold down a job in adulthood.

23. Seamus was a very determined young man and always pushed himself to try and live life to his best ability and in his own words he did not want to die and leave his 16 year old daughter.

24. Shea suffered in his last few days of life. He squealed in pain to be propped up in bed and/or to have so much as a sheet resting on his skin. He begged for two more months to live. He said "please, just two more months." It was terrible and the memory haunts me. Brutal, hurtful and a disgrace is all I can say to try to describe how Shea was neglected and left to suffer having suffered his whole life. Liver cancer and the pain he had to his joints from bleeds rendered him bed ridden and completely dependent on basic care at the end of his last few days. I would love to sit face to face with someone able to account for what has happened to him as we have so much of Shea's life we could share. He was taken so unfairly from us. I would like to hear the words "sorry" and a proper "sorry".

25. Eddie cried when Shea died. We have just been told that Eddie too has tumours and cirrhosis of the liver. We only found out because, at an appointment at the end of November last year, Tina demanded a copy of Eddie's bloods having been told by Dr Cash that Eddie was okay on the morning of his appointment and told by Dr MacDougall that same afternoon that Eddie had cirrhosis. We have now lost all trust with the medical profession when they so blatantly try to pull the wool over your eyes.

Section 6. Treatment/Care/Support

26. 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.

27. I refer to **Exhibit WITN2765003** 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. As stated, I believe Shea's lack of bone density to have been an issue left ignored by his medical team.

Section 7. Financial Assistance

28. Shea had received Stage 1 and Stage 2 Skipton payments.

Section 8. Other Issues

29. There are no other issues.

Anonymity, disclosure and redaction

30. 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. 3/5/2019

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).*